

**Information, Support and Parental Stress in  
Families with a Child with a Learning Disability:  
The Role of Diagnosis**

**Rhiannon Howie-Davies**

**This thesis is submitted in part fulfilment of the  
requirements for the degree of  
Doctorate of Clinical Psychology at  
The University of Edinburgh  
2006**



## DClinPsychol Declaration of own work

*This sheet must be filled in (each box ticked to show that the condition has been met), signed and dated, and included with all assessments - work will not be marked unless this is done*

**Name:** RHIANNON HOWIE-DAVIES

**Assessed work**

CS

SSR

Professional Issues

Thesis

(please circle)

**Title of work:**

INFORMATION, SUPPORT AND PARENTAL STRESS IN FAMILIES  
WITH A CHILD WITH A LEARNING DISABILITY: THE  
ROLE OF DIAGNOSIS

*I confirm that all this work is my own except where indicated, and that I have:*

- Clearly referenced/listed all sources as appropriate ☒
- Referenced and put in inverted commas any quoted text of more than three words (from books, web, etc) ☒
- Given the sources of all pictures, data etc. that are not my own ☒
- Not made undue use of essay(s) of any other student(s) either past or present (or where used, this has been referenced appropriately) ☒
- Not sought or used the help of any external professional agencies for the work (or where used, this has been referenced appropriately) ☒
- Acknowledged in appropriate places any help that I have received from others (e.g. fellow students, technicians, statisticians, external sources) ☒

I understand that any false claim for this work will be penalised in accordance with the University regulations ☒

**Signature** .....

**Date** .....18/10/06.....

### **Please note:**

a) If you need further guidance on plagiarism, you can:

i/ Speak to your director of studies or supervisor

ii/ View university regulations at <http://www.aaps.ed.ac.uk/regulations/Plagiarism/Intro.htm>

b) Referencing for all assessed work should be in the format of the BPS style guide, which is freely available from the BPS web site

The thesis has been composed by the candidate and the work is my own. The work has not been submitted for any other degree or professional qualification.

Signed

# Contents

<b>Abstract</b>	1
<b>Introduction</b>	2
<b>Section one: Definitions and context</b>	4
1.1 Definition of learning disability	4
1.12 Assessment of learning disability	5
1.121 Difficulties with assessment of intellectual functioning	6
1.122 Difficulties with assessing adaptive behaviour	7
1.123 The concept of learning disability	8
1.2 Prevalence of learning disability in children	10
1.3 Causes of a learning disability	11
1.31 Pre-natal causes	12
1.32 Peri-natal causes	13
1.33 Post-natal causes	13
1.34 Unknown causes	14
1.4 Use of terminology	14
1.41 Individuals with the non-specific diagnosis 'learning disability'	14
1.42 Individuals with a specific diagnosis	16
1.5 Children with a learning disability	17
1.51 Terminology used in relation to children	17
 Section one summary	 20
 <b>Section two: Families with a child with a learning disability</b>	 22
2.1 Diagnosis	22
2.11 The process of diagnosis and information provision	22
2.12 The impact of diagnosis	24
2.2 The positive impact of having a child with a learning disability	26
 Section two summary	 28



<b>Section three: Stress in families with a child with a learning disability</b>	<b>29</b>
3.1 Parental mental health	30
3.2 Factors mediating the stress experienced by families with a child with a learning disability	32
3.21 Child factors	
3.211 The nature of a child's difficulties as a factor in parental stress	33
3.212 The impact of the specific diagnosis on stress	36
3.22 Parent factors	40
3.221 Parental beliefs, cognitions and coping strategies	40
3.222 Differences in mothers' and fathers' stress	43
3.23 Social factors	44
3.3 The role of support and information in the stress experienced by families	45
3.31 The effect of support on stress	45
3.32 Informal support	46
3.33 Professional services support	48
3.34 Information and stress	50
Section three summary	50
<b>Section four: Introduction summary</b>	<b>52</b>
4.1 Research with families with a child with a learning disability	55
<b>Section five: Thesis Rationale/Aims</b>	<b>56</b>
5.1 Hypotheses	58
<b>Methods</b>	<b>59</b>
Systematic literature review	59
Study design	59
Procedure	60
Ethics	61
Participants	62

Measures	62
Demographic, diagnosis and information questionnaire	62
Scoring system	63
Objectivity	64
Validity	64
Content validity	65
Face validity	66
Social validity	66
Reliability	66
 A Short Form of the Questionnaire on Resources and Stress	67
The Family Support Scale	68
Power Analysis	69
Statistical Analysis	69
 <b>Results</b>	70
Demographic information	70
Age of children	70
Age of child at diagnosis	71
Diagnoses	71
Terminology	72
Understanding of terminology	73
 Inter-rater reliability of the demographic, diagnosis and information Questionnaire	74
 Reliability of the QRS-F and Family Support Scale	75
 Results relating to hypotheses	75
Hypothesis one	76
Number of sources from which parents had accessed information	77
Amount of information received from sources	77
Mean satisfaction rating for information received	78

Hypothesis two	79
Parents accessing information from support organisations	79
Amount of information from support organisation	80
Satisfaction with information from support organisations	80
Hypothesis three	81
Total number of professional services available as support	81
Level of helpfulness of professional services	82
Hypothesis four	82
Total perceived stress	83
Parent and family problems	83
Pessimism	84
Hypothesis five	85
Information and Support	85
Stress	85
Analysis of further comments	86
Impact of a non-specific diagnosis	86
Rare conditions	87
Information provision	87
Not being listened to	88
Other parents	89
Positive comments	89
<b>Discussion</b>	91
<b>Section one: Discussion of results</b>	91
1.1 Aims of the current study	91
1.2 Summary and discussion of results	92
1.21 Demographic information	92
1.22 Reliability	94
1.23 Results relating to hypotheses	95
1.231 Hypothesis one	95

1.232 Hypothesis two	97
1.233 Hypothesis three	101
1.234 Hypothesis four	103
1.235 Hypothesis five	106
1.24 Parental comments	109
1.241 The impact of a non-specific diagnosis	110
1.242 The impact of a rare diagnosis	111
1.243 Information provision	111
1.244 Not being listened to	113
1.245 Other parents	113
1.246 Positive comments	114

## **Section two: Clinical and ethical implications of the current research** 114

2.1 The diagnostic process and provision of information	114
2.2 Terminology use	117
2.3 Support from professionals	119

## **Section three: Methodological issues of the current study** 120

3.1 Methodological limitations	120
3.11 Sample size	120
3.12 Representativeness of sample	121
3.13 Mediating factors and parental stress	122
3.14 Questionnaire	123
3.15 Statistical limitations	126
3.2 Methodological strengths	127

## **Section four: Further research** 128

4.1 Information provision	128
4.2 Learning disability terminology	129
4.3 Support Organisations	130

<b>Section five: Summary and conclusions</b>	131
<b>References</b>	133
<b>Appendices</b>	145
Appendix I: Definitions of learning disability/mental retardation	145
Appendix II: Systematic review of literature used in the introduction	146
Appendix III: Demographic, diagnosis and information questionnaire	168
Appendix IV: Inter-rater reliability of the demographic, diagnosis and information questionnaire	171
Appendix V: Family Support Scale	173
Appendix VI: A Short-Form of the Questionnaire on Resources and Stress	174
Appendix VII: Information sheet and consent form	177
Appendix VIII: Correspondence with Stirling Council regarding ethical approval	181
Appendix IX: Correspondence with Clackmannanshire Council regarding ethical approval	187
Appendix X: Correspondence with Edinburgh City Council regarding ethical approval	191

Word count: 29, 996

## **Abstract**

Research on stress in parents with a child with a learning disability, has found many different factors which impact on stress. One of these factors is support, however there has been little research on the effect of information provision on parental stress. This study investigates differences in information, support and stress between families with a child with a specific and non-specific learning disability diagnosis. The relationship between information, support and stress is also investigated.

Methods: The sample consisted of 24 parents of children with a non-specific diagnosis and 23 parents of children with a specific diagnosis. Parents completed a demographic, diagnosis and information questionnaire, the Family Support Scale, and a short-form of the Questionnaire on Resources and Stress.

Results: Parents of children with a specific diagnosis had accessed significantly more sources of information and were more likely to have accessed a support organisation. However there were found to be no differences between the two groups regarding the amount of and satisfaction with the information and support received. There were no significant relationships between the information or support variables and perceived parental stress.

Conclusions: The main difference between parents of a child with a specific and non-specific learning disability diagnosis appears to be accessibility rather than quality of information and support available. This is an area that warrants further research investigation.

## **Introduction**

Having a child with a learning disability can place increased stress on parents and families. The initial discovery that their child has a leaning disability can be greeted with feelings of shock and distress which can be seen as a grieving process, (Maxwell and Barr 2003). Appropriate information and the way in which this information is given to parents at the diagnosis can impact on parental satisfaction with the diagnostic process (Quine and Rutter, 1994). Throughout the life course of individuals with a learning disability their family is likely to be the main source of support, and as such the families themselves can experience stress in trying to meet that individuals' needs. Families with a child with a learning disability have been found to experience greater levels of stress, in relation to their child, than families whose children do not have a learning disability, (Dyson, 1993, 1997). Such research findings, however, can fail to acknowledge that the term 'learning disability' encompasses individuals with a vast array of different needs. Likewise, it can have a wide range of causes from genetic syndromes, to accidents and infections before or after birth. It is, therefore, unlikely that a simple relationship exists between a child having a learning disability and parental stress.

The term 'learning disability' is used within health and social care settings within the UK; however the term is often misunderstood and misused due to a lack of knowledge about its exact meaning. This is compounded by the use of different terms in different countries, particularly America, where the term 'mental retardation' is used and learning disability is used to refer to learning

difficulties such as dyslexia. Within the UK, the terms learning disability and learning difficulty are often used interchangeably which can lead to the exact nature of an individuals' needs not being understood and subsequently not met. This lack of knowledge and understanding of terminology can extend to professionals (McKenzie, Murray, Matheson, Higgon & Sinclair, 1999) and, as a result, parents can be left without clear information regarding their child's difficulties and access to appropriate support. By contrast, the discovery that a child is diagnosed as having a learning disability can lead to relief for the family, giving a sense of knowing what it is the family is dealing with, rather than the state of not knowing but feeling that something isn't right, (Maxwell and Barr, 2003).

The diagnosis of a learning disability can come very early for some children. For others it can take years of parents pursuing professionals in search of an explanation for their child's difficulties. A delayed diagnosis is perhaps more likely when the cause of the learning disability is unknown or is not related to an easily recognised syndrome or disorder (Quine & Rutter, 1994). Thus the cause of the learning disability and process of getting a diagnosis could influence the stress experienced by parents. The current thesis aims to explore the extent to which parents of a child with a learning disability received appropriate information and support; whether this differed according to whether the child had a specific syndrome or unspecified cause of learning disability and how this relates to parental stress.



The introduction will begin with an outline of the definitions of learning disability commonly used in the UK. This will be followed by a discussion of the main causes of a learning disability. The next section will focus on the debate about the confusion and lack of knowledge amongst professionals regarding learning disability terminology and the ways in which this may impact on the information and support available to parents. The introduction will end with an outline of the literature on stress in parents of a child with a learning disability, before the aims and hypotheses of the study are presented.

## **Section One: Definitions and context**

The accurate diagnosis of, identification of needs and provision of appropriate support to, people with a learning disability begins with a clear understanding of the definition of learning disability and how this is assessed. The following section, will therefore, provide a brief overview of these two areas.

### *1.1 Definition of Learning Disability*

In the UK 'learning disability' is currently the most widely used term in health and social care settings to describe what was previously known as 'mental handicap'. The British Psychological Society (BPS) (2000) sets out three core criteria for learning disability:

- Significant impairment of intellectual functioning
- Significant impairment of adaptive/social functioning
- Age of onset before adulthood

The BPS highlights the need for the individual to meet all three criteria in order for a classification of learning disability to be made. These three criteria are also central to the definitions provided by American Association on Mental Retardation (AAMR) and the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders, (DSM-IV). The criteria for the AAMR (2006) and the DSM-IV (APA, 1994) definition of mental retardation can be found in Appendix I.

Perhaps one of the more user friendly definitions is that in the Scottish Executive document 'The same as you?' which states that

"people with learning disabilities have a significant, lifelong condition that started before adulthood, that affected their development and which means they need help to: understand information, learn skills and cope independently" (Scottish Executive, 2000, p 2).

This definition provides more practical information that is easily understood by a lay person about what someone with a learning disability might have difficulties with. It does, however, fail to give guidance on how such difficulties might be measured in practice.

### *1.12 Assessment of a learning disability*

The BPS recommends that both intellectual and adaptive functioning are assessed before a classification of learning disability is made. If terminology is to be used appropriately then accurate assessment of learning disability is

essential to determine whether or not an individual should be referred to as having a learning disability.

#### *1.121 Difficulties with assessment of intellectual functioning*

The most commonly used measure of intellectual functioning is the Wechsler Adult Intelligence Scale, 3<sup>rd</sup> edition (WAIS-III) (Wechsler, 1997). However, there are difficulties with such measures of intelligence which include a lack of standardisation using a learning disability population incorporating a range of severity and the use of a formal testing situation which could induce anxiety and affect performance, (Emerson, 1998). Furthermore the WAIS-III includes many items that require knowledge gained from formal education, thus placing those who have not attended mainstream schools at a disadvantage (Kaufman and Lichtenberger, 1999). A further consideration noted by the BPS (2000) is that the existing assessment measures are not reliable and valid enough for use with people with very low intellectual functioning. Thus formal assessment of intellectual functioning is not always an accurate or appropriate way of determining whether someone has a learning disability. Despite the limitations of intellectual assessment, the Wechsler scales are one of the best researched tools in terms of validity and reliability (Lezak, Howieson, Loring, Hannay & Fischer, 2004). This contrasts with assessments of adaptive function, which have less research about their validity and reliability.

### *1.122 Difficulties with assessing adaptive behaviour*

Assessment of adaptive/social functioning is a lot less clear cut as it is such a broad term. However it is generally seen to relate to a person's ability to function in everyday life, encompassing activities such as washing and dressing, compared to what is expected for someone of their age and the society they live in. Assessment of adaptive functioning often involves an informant-based measure such as the Vineland Adaptive Behaviour Scale (Sparrow, Balla & Cicchetti, 1984). Such measures have obvious limitations as the informant may under or overestimate the person's abilities. This is particularly relevant to the learning disability population where basic knowledge about learning disability amongst care staff has been found to be limited (McKenzie et al., 1999a). The BPS (2000) recommends that assessment of adaptive functioning should ideally involve more than one informant and be done on more than one occasion. This again is particularly difficult in learning disability services where there is a high turn-over of staff resulting from burn-out and stress (Sharrad, 1992). Thus finding an informant who has been in post long enough to know the individual well and is likely to be available for a return assessment can be difficult. The BPS (2000) recognises the difficulties in assessing adaptive functioning but recommends "the use of a formal assessment of adaptive/social functioning should be seen as good practice" (page 7).

The third criterion of a learning disability, age of onset, is much clearer cut, although the importance of recognising the difference between someone who had such impairments since infancy and someone who acquired such

impairments as a result of a brain injury in later childhood is highlighted by the BPS (2000).

While the criteria for a learning disability are clear and consistent across different countries, there are difficulties in reliably and accurately measuring each of the three components. This has led to some debate about which group of people should actually be considered to have a learning disability.

#### *1.123 The concept of learning disability*

The concept of learning disability is a social construction which relies on assessment tools which have certain limitations, as outlined above. A number of authors have addressed the issue of the influence that these factors may have on determining who can be considered to have a learning disability.

Whitaker (2004), in his paper considering the prevalence of those with learning disability and the proportion known to services, highlights that there are actually four different groups of people who could be regarded as having a learning disability. These cover those who meet only one criteria of intellectual impairment or adaptive functioning, those who meet all criteria but are not known to services and finally those who meet all criteria and are actually in contact with specialist learning disability services.

This illustrates how the term learning disability can be confusing and it is not always clear who it directly refers to, as all of the above could be considered to have a learning disability and warrant specialist learning disability services.

Whilst Whittaker (2004) based his conclusions on data from only one part of the UK it seems likely that his conclusions could be generalised to the UK as a whole.

Thus the difficulties of assessment outlined above coupled with the issue of disparity between who actually fits criteria and who is receiving learning disability services contributes to the confusion of when learning disability terminology is used and whether it is used appropriately and accurately.

In addition, people with learning disabilities are not a homogenous group and the term encompasses many different difficulties and levels of severity. It includes people with a specific syndrome such as Down syndrome, those with difficulties such as Autistic Spectrum Disorder and those without any diagnosis except a learning disability. Autistic Spectrum Disorder (ASD) is particularly complex, and, as the name suggests it covers a broad spectrum of difficulties. People with ASD usually have what is referred to as the 'triad of impairments' which encompasses difficulties with social interaction, communication and imagination, (National Autistic Society, 2006). People with ASD can and often do have a learning disability but everyone with ASD does not meet the learning disability criteria. Despite people with ASD not always meeting the full criteria for a learning disability they may still be referred to and some will be seen by learning disability services as these best meet their needs. However, learning disability services vary regarding whether they will see those who don't strictly meet learning disability criteria.

In summary, while the terminology and precise definitions used to describe the concept 'learning disability' may differ in some respects, there is agreement on the three core components of: intellectual impairment; difficulties in adaptive functioning and an onset before the individual is 18 years old. However the causes of such difficulties are many and despite the three key components being present for all with a learning disability, the cause, severity of the difficulties and ways in which they manifest vary with each person and more specific diagnoses. An outline of prevalence rates and some of the main causes of a learning disability will be given in the following section.

### *1.2 Prevalence of learning disability in children*

The prevalence of learning disabilities is growing due to improved survival rates for those with complex medical needs, and an increase in life expectancy in the general population. It is estimated that there are approximately 120,000 people in Scotland with a learning disability and about a quarter of these are under 16, (NHS Quality Improvement Scotland, 2004). Of these 120,000 people, it is estimated that only 30,000 are regularly in contact with social or health services in Scotland, (Scottish Executive, 2000). With the increase in survival rates, children with very severe physical and learning disabilities are now surviving. Previously children with a severe learning disability and accompanying physical difficulties would not have survived or if they did would not be expected to be cared for at home (Thomson, 1996). Families can now be caring for children with a very high level of need. When considering the impact on families it must

be remembered that some are now supporting on a long-term basis children with very complex needs.

### *1.3 The causes of a learning disability*

As Hatton (1998) notes, understanding the cause of a person's learning disability can have important implications for the treatment of the particular difficulties which that individual may experience. However, for some people there is no easy explanation for their learning disability. Statistics on the prevalence and aetiology of learning disability vary, with estimates of around three to four per 1000 people (0.3-0.4%) having a learning disability and of these up to half having an unknown aetiology, (McLaren and Bryson, 1987). These figures come from a review of several epidemiology studies from different countries and thus are likely to be more representative than a single study. Similar figures were found in a more recent Finnish study which found the prevalence of learning disability to be 0.43% with 0.13% having a severe or profound learning disability. Of those with a severe or profound learning disability the aetiology was found to be genetic or congenital in 50.9% of cases and unknown in 11.5% of cases, (Arvio & Sillanpaa, 2003). This suggests that for many people the exact cause of their learning disability is unknown particularly for those with mild to moderate levels of learning disability.



### *1.31 Pre-natal causes*

The most common pre-natal cause of a learning disability is chromosomal abnormalities, with the most common of these being Down syndrome.

Wellesley, Hockey and Stanley (1991) examined a large sample of Australian children with regard to aetiology of learning disability. They found that chromosomal abnormalities accounted for 42% of prenatal causes of a learning disability and of these 90% were Down syndrome. Diagnosis of a chromosomal disorder such as Down syndrome does not however give any indication of how severe any learning disability will be.

Other prenatal causes can include single gene disorders such as Fragile X syndrome. While Fragile X is a commonly inherited cause of a learning disability, not all those who inherit the gene have a learning disability. In particular females are often carriers with only around 30% having a learning disability (Sherman, Jacobs, Morton, Froster-Iskenius, Howard-Peebles, Nielsen, Partington, Sutherland, Turner & Watson, 1985). There are also syndromes with unknown genetic aetiology, such as Williams syndrome, along with metabolic and congenital abnormalities of unknown origin that can account for around 25% of prenatal causes of a learning disability (Wellesley et al. 1991).

Environmental factors, including infections during pregnancy and alcohol and substance use during pregnancy have also been found to be a significant pre-natal cause of a learning disability, accounting for up to 11% of those with a learning disability (McLaren & Bryson, 1987).

### *1.32 Peri-natal causes*

Perhaps the most common peri-natal cause of a learning disability is hypoxia, the brain being starved of oxygen, at the time of birth. Wellesley et al. (1991) found hypoxia to account for 68% of the peri-natal causes of a learning disability although peri-natal causes only accounted for 10% of their sample. Intra-uterine infections can also be a peri-natal cause of a learning disability accounting for between 2 and 6% of those with a severe learning disability (McLaren & Bryson, 1987).

### *1.33 Post-natal causes*

There is less known about post-natal causes of a learning disability, but they include infections, such as meningitis, and trauma, such as head injuries. Up to 13% of those with a severe learning disability were found to have a postnatal cause by McLaren and Bryson, (1987). They do note, however, that rates vary considerably across studies possibly due to differences in healthcare moderating the effects of infections. In addition, the fact that the third criterion for a learning disability is an age of onset before 18 (BPS, 2000) means that a learning disability could be caused by a range of post natal causes at any stage in a child's development, creating a diverse population with varying needs. For example, the needs of someone with an acquired head injury and previously normal intellectual functioning are likely to be very different to someone who has had a learning disability since birth.

### *1.34 Unknown causes*

It is important to note that for many people the cause of their learning disability is unknown. Estimates range from 15 to 40% for those with a severe learning disability and up to 63% for those with a mild learning disability, (McLaren and Bryson, 1987). It is also important to highlight that knowing the cause of the disability such as pre, peri or post-natal infection, does not give any information about the likely severity, prognosis and manifestations of the learning disability.

As has been shown above, the specific cause of a learning disability can be varied and can occur at different stages of a child's development. For many individuals, the cause of their learning disability may be unknown. In addition, because the needs of people who have a learning disability are so varied, having the diagnosis may not, in and of itself, help inform parents and others about the nature of a child's difficulties. This is discussed further in the section below.

## *1.4 The use of terminology*

### *1.41 Individuals with the non-specific diagnosis 'learning disability'*

Individuals with the diagnosis 'learning disability' are likely to have a variety of additional labels attached to them throughout their lives. Such labels may include global delay, developmental delay, learning difficulties, special needs and intellectual disability (Emerson, Hatton, Bromley & Caine, 1998). The numerous labels and terminology used can be confusing, particularly as they may be used interchangeably, their exact meaning may be unclear or they may

be used incorrectly. For example, the term 'learning difficulty' may be used in educational settings to describe both children with a learning disability and those with specific cognitive difficulties, such as dyslexia. Indeed there are some who feel the term learning disability does not truly reflect the nature of the individual's difficulties and is used only out of political correctness, (Gates, 1997). Such confusion of terms can lead to a misunderstanding of the needs of the individual concerned. Gates (1997) notes that by using one term to describe such a wide range of people and difficulties, the needs of people with a learning disability may at times be denied. In particular he highlights that there are likely to be people with learning disability

"whose needs are not being met because the 'soft' politically correct terminology denies the reality and complexity of their needs". (p51).

However it must be borne in mind that these are Gates (1997) own personal views of the use of learning disability terminology put forward in an editorial piece and do not include data on how widely held such views are.

There is much debate about the correct terminology to use and whilst learning disability is the term most commonly found in the UK research literature and policy documents, it is not necessarily used or used correctly by those working in the field. Research has shown that many professionals lack knowledge about what a learning disability is. McKenzie et al. (1999a) studied the understanding of the term learning disability amongst a variety of professionals working with people with a learning disability. They compared people's response to the

question ‘what is your understanding of the term learning disability?’ with the DSM-IV criteria. They found that the majority of each staff group correctly identified intellectual impairment as one of the criteria. However, with the exclusion of those working in health settings far fewer identified impairment in adaptive functioning and childhood onset. Perhaps most revealing is the low numbers who were aware of all three criteria: 2% residential staff, 2.6% day care staff, 36.2% of those working in health settings and worryingly only 3.7% of GPs. Whilst the study only involved one small part of the UK, a wide range of professionals were included from a range of services thus providing data on knowledge across professions and different health and social care settings.

The authors suggest that this limited knowledge base amongst staff who support people with a learning disability may be partly attributable to the frequent changes in terminology. The following section examines whether there is more clarity in relation to people with a more specific diagnosis.

#### *1.42 Individuals with a specific diagnosis*

Researchers have examined the extent to which having a specific diagnosis can impact on the knowledge of professional staff and the extent to which this varies with the rarity of the condition. One example is Fragile X syndrome, an inherited disorder which is relatively rare but for which there do exist medical diagnostic tests. Fragile X has a particular behavioural and cognitive profile which could impact on a child’s educational and health service needs. York, von Fraunhofer, Turk & Sedgwick, (1999) compared the knowledge of teachers working in special and mainstream education about three specific diagnoses

within learning disability. These were Down syndrome, Autism and Fragile X. They found that the vast majority of teachers, including those working in mainstream education, had a clear idea of the main features of Down syndrome and Autism. Very few, however, demonstrated clear knowledge of what the diagnosis of Fragile X would mean for a child's educational needs. York et al. (1999) used a relatively large sample including both special and mainstream school staff suggesting such findings may be replicated elsewhere. This suggests that there is a relationship between the rarity of the diagnosis and teacher knowledge about it. If such a relationship held true across other professional groups, this would suggest that parents of children with either a non-specific diagnosis of learning disability (McKenzie et al., 1999a) or a rarer specific diagnosis may receive support and information from staff that have limited knowledge about their child's condition and needs.

### *1.5 Children with a learning disability*

#### *1.51 Terminology used in relation to children*

Adults with a learning disability primarily come in to contact with health and social care services which, in theory, should all be using the term 'learning disability'. As we have seen, this is not always the case and misunderstandings about terminology are common (McKenzie et al., 1999a). In the case of children with a learning disability there is also the involvement of education services. Education services tend to use the terminology 'learning difficulties' 'additional support needs' or 'special educational needs' amongst others to refer to children with a learning disability (Education (Additional Support for

Learning) (Scotland) Act 2004). This also coincides with an increasing emphasis on needs based service provision which prioritises assessing need without actually giving the child any label including a diagnosis of learning disability (Education (Additional Support for Learning) (Scotland) Act 2004). Unfortunately, this approach can make it difficult to determine the prevalence of learning disability or focus on the needs of the learning disability population. Needs based service provision means that there are children who would not meet the criteria for a learning disability but who do have a record of their educational needs. For example, a child with dyslexia may have additional support needs and thus warrant a record of educational needs, but would not be considered to have a learning disability.

The Education (Additional Support for Learning) (Scotland) Act 2004 expressly moves away from the idea of special educational needs and seeks to look at those who might need extra support within education for a wide variety of reasons. One of the key changes is the use of the term 'additional support needs' which includes anyone who experiences a barrier to learning whether through social, emotional, cognitive, disability, or family circumstances. Thus those receiving additional support for learning will be a large heterogeneous group from those with a learning disability, to a child who is bullied, to a child in the care system. The Act is therefore likely to make research in the field of children with a learning disability more difficult, as without individual assessment, it is difficult to determine and define the population being studied.



The change in education provision for children with a learning disability or other 'special needs' is going through a period of great change with a move away from 'special schools' towards far greater inclusion within mainstream schools. Inclusion can often be in the form of having extra support in a mainstream class or having some lessons in an extended support unit based within the school and other classes with age peers. Whilst this might doubtless have some advantages through encouraging integration and understanding of disabilities, it again makes children with a learning disability difficult to identify, particularly those with a mild learning disability.

While the Education (Additional Support for Learning) (Scotland) Act 2004 was intended to be the legal basis for parents getting the correct support for their child, it at no point uses the term learning disability. This may make it more difficult for parents to identify learning disability services as appropriate for their child.

Thus the question of terminology is even more complex with children with a learning disability due to their involvement with an education system that does not use the term learning disability. It also raises questions for service provision; when different services, such as health and education, use different terminology it is easy to see how referral between these services will not always be straightforward. Whilst the correct use of terminology should facilitate the process of families receiving appropriate help and support, one can see that the use of different terminology between services could lead to confusion for families and professionals. With the changes in the care and education of



people with a learning disability they are becoming a more visible population and the need for clear communication between services cannot be ignored.

### *Section one summary*

There are three key criteria for a learning disability: intellectual impairment, adaptive functioning impairment and an onset before adulthood. These criteria are generally agreed on by the key professional bodies (BPS, 2000 and AAMR, 2002) and the main diagnostic manual, DSM-IV (American Psychiatric Association, 2004). The terminology, however, differs between countries, with the UK referring to learning disability and North America and much of Northern Europe using the term mental retardation. There are difficulties assessing the three criteria, particularly in the area of adaptive functioning which is not easily defined or assessed. The term learning disability is generally accepted in UK health and social care settings; however professionals working in the area have been shown to have limited knowledge of the meaning of the term learning disability, (McKenzie et al., 1999a). There are varying causes of learning disability from pre-natal causes such as chromosomal disorders like Down syndrome, to peri-natal causes such as hypoxia at birth and post-natal infections and accidents. There are also a significant proportion of people for whom the cause of their learning disability is unknown. Having a specific cause and more specific diagnosis can lead to parents gaining more information and support, however when the diagnosis is of a rarer disorder professionals' knowledge can again be limited, (York et al. 1999). There are also disorders such as ASD where individuals may or may not have an associated learning disability, but in

some cases are able to access learning disability services whilst others are unable to access learning disability or mainstream services.

As the causes and diagnoses of the learning disability population vary, so do the severity and nature of their difficulties and as such they should not be considered a homogenous group. The terminology used by different services can have direct implications for the support a family is able to access. This is particularly relevant to education, as the Education (Additional Support for Learning) (Scotland) Act 2004 has no mention of the term learning disability, yet is supposed to address the needs of the learning disability population amongst others. The population of children with a learning disability is growing including those with particularly complex needs. Families are therefore caring for their children with a learning disability in an environment where access to support and information is extremely variable. The impact of these differences is important to consider if services are ever to become truly needs led and person-centred.

The following section provides an overview on the effect on families whose child receives a learning disability diagnosis; their experience of the diagnostic process and their personal reaction to receiving the news of the diagnosis.

## **Section Two: Families with a child with a learning disability**

Children with a learning disability and their families in particular are the focus of the current study. Service provision for children with a learning disability has changed considerably over the years (Caine, Hatton & Emerson, 1998); this has resulted in a change in the challenges, emotional and practical, that face parents of a child with a learning disability. Parents of a child with a learning disability were previously encouraged, sometimes against their wishes, to have their child placed in an institution, leading to emotionally painful separations of parents and children, (Thomson, 1996). Today parents are expected and encouraged to look after their child at home even when they have very complex difficulties (Caine et al., 1998). People with a learning disability can have difficulties with many aspects of self-care and functioning required for independent living and thus can often be highly dependent on the help and care of others (BPS, 2000). In the case of children with a learning disability this need for support and care is usually met by the family. The impact on a family can change over time from the shock of initial diagnosis to meeting the changing needs of the child as they develop.

### *2.1 Diagnosis*

#### *2.11 The process of diagnosis and information provision*

The process of a child receiving a diagnosis of learning disability can vary dramatically, (Quine & Rutter, 1994). Communication between medical staff and parents regarding such diagnoses has improved over the years but parents are still not always receiving the information and support they need at the time

of diagnosis (Carmichael, Pembrey, Turner & Barnicoat, 1999, Quine & Rutter, 1994).

Quine and Rutter (1994) investigated parents' dissatisfaction with the way they were informed of their child's diagnosis in a relatively large sample drawn from one area in the south of England. They found that, in total, 58% of parents were dissatisfied with the way they were first told of their child's disability.

Interestingly they found a significant relationship between the age of the child at diagnosis and parental satisfaction. They conducted detailed analysis of factors related to parental satisfaction and a key factor was the nature and timing of the diagnosis. Quine and Rutter (1994) also found that when the learning disability had an easily identifiable cause, such as Down syndrome, parents were more likely to be told at or shortly after birth. By contrast, of those whose learning disability was due to an unknown cause, only 32% had been identified by the time the child was one. Furthermore specific diagnoses were associated with higher parental satisfaction with the way they were informed of the diagnosis than diagnoses of non-specific learning disability. Quine and Rutter (1994) suggest that the difference in satisfaction may be related to those whose child has a non-specific learning disability having spent greater time waiting and worrying before they are given a diagnosis. There is also the possibility that such parents have had to wait longer before receiving the information and support that a diagnosis can bring. Quine & Rutter (1994) also found that many parents described it as hard to get information about their child's difficulties and nearly three quarters wanted more information than had been provided.

Carmichael et al., (1999) explored the experiences of parents whose children had received a diagnosis of Fragile X syndrome. Parents were sent a questionnaire with open-ended questions regarding their experience of diagnosis. Only just over 20% reported feeling that their treatment by medical staff at the time of diagnosis was caring and supportive. Some reported adverse experiences in seeking a diagnosis with examples of people being told they were over-anxious neurotic mothers, that the difficulties were a result of their parenting and that the child would grow out of the difficulties. Positive comments regarding the way the diagnosis was given focussed on being dealt with in a sensitive way and provided with appropriate information and access to support. The provision of written material was particularly welcomed as something to refer to once getting over the initial shock of diagnosis. Negative experiences were associated with lack of information and follow-up support. Importantly the authors highlight that their sample was drawn from members of the Fragile-X society and thus were likely to be parents who are more able to access support. They suggest that if these parents are reporting negative experiences of diagnoses; then those who may be less able to access supports maybe even more adversely affected by negative experiences during the diagnostic process.

### *2.12 The impact of diagnosis*

Discovering that your child has a learning disability will always provoke an emotional reaction whether the diagnosis comes as a complete surprise or after months or even years spent trying to discover what is ‘wrong’ with your child. Many describe an initial reaction of shock and disbelief, which some describe as

similar to bereavement, (Maxwell, 1993, Maxwell & Barr, 2003). The importance of including fathers in the process of diagnosis is emphasised as necessary for both the mother and father's adjustment (Maxwell, 1993, Rendall, 1997).

The cause of the child's learning disability can also impact on parents' adjustment, particularly if the cause is found to be genetic (Maxwell & Barr, 2003). With the advances in the field of genetics many parents can see this as an answer to their questions; although Barr (1999) highlights that the possible negative effects such as issues of blame and guilt and their impact on family relationships have been little studied. Barr (1999) also raises the fact that parents can undergo genetic counselling in hope of discovering the cause of their child's difficulties and yet despite all the tests end up without a conclusive cause, resulting in feelings of disappointment. It is important to note that Barr's (1999) conclusions are the result of his own consideration of the literature and personal experience, rather than a detailed study of the effects on parents of genetic counselling

Hall and Marteau (2003) explored the role of causal attributions and blame in the adjustment of mothers to having a child with Down syndrome. They found that mothers who blamed others for the Down syndrome had higher anger, anxiety, parenting stress and more negative attitudes towards their child than mothers who either made no attributions to others or only causal attributions. Hall and Marteau (2003) note however, that blame and attributions are difficult

concepts to measure and it will always be difficult to ascertain an individual's attributional style from a one off assessment.

The initial discovery that a child has a learning disability can lead to feelings of shock and grief even when parents have suspected that 'something isn't right'. It appears that part of the difficulty in adapting to a child with a learning disability is having to mourn the loss of the healthy child that the parents were expecting to have, along with finding themselves in a more demanding care situation than they had ever expected (Maxwell & Barr, 2003). The unexpectedness and shattering of the envisaged child and future seems to be key in the adjustment process, (Maxwell & Barr, 2003, Rendall, 1997). This is supported by the findings that adoptive families who knew that their child had a learning disability before they came into their lives, had lower levels of depression and appeared to cope better than birth families (Glidden & Pursley, 1989, Glidden & Schoolcraft, 2003). Having a child with a learning disability, should not, however, be viewed as automatically having a negative impact on the family. Research has found that for many families the experience can be positive. This is discussed in more detail in the next section.

## *2.2 Positive impact of having a child with a learning disability*

Before considering the stress families with a child with a learning disability experience it is important to note that there can be a positive impact on families of having such a child. Grant, Ramcharan, McGrath, Nolan & Keady, (1998) found that family care-givers of people with a learning disability reported stresses but also rewards and gratifications of the care giving experience. They



found that perceiving care-giving tasks to have clear benefits to the person with intellectual disabilities, such as seeing improvements however small, helping them reach their full potential and seeing the person looking well-cared for, was a source of widespread satisfaction amongst family caregivers. Closer family relationships, appreciation from others and feeling needed/wanted were also sources of satisfaction for caregivers. This is one of the minority of studies that looks at both positive and negative aspects of the caregiving experience rather than the traditional focus on negative factors.

Hastings, Allen, McDermott & Still, (2002) found that positive perceptions of mothers of children with a learning disability were associated with similar factors to those that predict stress. They found that mothers' perceptions of the child as a source of happiness and fulfilment, strength and family closeness were associated with reframing coping strategies. They also found, importantly, that reframing coping strategies, the helpfulness and usefulness of support and care-giving demand were associated positively with mothers' perceptions of the child as a source of personal growth and maturity. Hastings et al. (2002a) did base their findings on a small sample however, as highlighted above it is important that research literature is beginning to include studies of the positive side of having a child with a learning disability.

The positive impact can also be seen in siblings of a child with a learning disability. Despite often having additional responsibilities, siblings often report having a positive relationship with their siblings and have been found to have increased empathy (Cuskelly & Gunn, 2003). These findings were from a



relatively large sample of well-matched siblings of children with and without Down syndrome. It is unclear, however, if these findings are similar for siblings of children with other causes of learning disability.

The findings outlined above suggest that having a child with a learning disability should not be viewed as a wholly negative experience and there can be some positive outcomes for families resulting from having a child with a learning disability. The positive impact a child with a learning disability can have on the family is important as it may have moderating effects on family stress. The stress experienced by families with a child with a learning disability is affected by many factors, including their perception of the child and caregiving situation. Thus a positive perception of the caregiving situation or feeling that there are benefits to having a child with a learning disability may impact on families' stress.

### *Section two summary*

With the change towards community care more children with a learning disability, regardless of severity are now being cared for at home by their family, (Caine et al., 1998). The process of a child receiving a diagnosis of learning disability can have a large impact on families, yet the way in which this information is delivered can be extremely variable, (Quine & Rutter, 1994). The timing of the diagnosis has been found to be particularly important, with earlier diagnosis, particularly if shortly after birth being associated with higher satisfaction with the diagnostic process amongst parents (Quine & Rutter,

1994). Receiving news of a child's learning disability is often described by parents in terms of shock and a grief like reaction, (Rendall, 1997, Maxwell & Barr, 2003). The shock element of the diagnosis can be important to a families' adjustment, as highlighted by studies of adoptive parents of children with a learning disability, who knew of the learning disability in advance of the adoption and were found to be coping very well and possibly better than birth parents, (Glidden & Pursley, 1998). It is also important to note that there are positive aspects of having a child with a learning disability, including finding the child and caregiving situation a source of satisfaction and fulfilment, (Grant et al., 1998, Hastings et al., 2002a). For families, however, having a child with a learning disability can, at times, be a source of stress. This is explored further in section three, below.

### **Section Three: Stress in families with a child with a learning disability**

The stress that families with a child with a learning disability experience has been increasingly studied over the years. Parenting any child can be stressful at times but when that child has additional needs in terms of care and support, which may necessitate involvement from a variety of services, this may understandably, bring additional stress to the family. Dyson (1993) conducted a longitudinal study of a group of parents, with some having a child with a disability and the others having children without a disability. She found that, whilst stress and family functioning remained relatively stable over time, families whose child had a disability had significantly higher stress levels than families whose child did not have a disability. Roach, Orsmond & Barratt, (1999) in a comparison of families who had a child with Down syndrome and

families with typically developing children, found that the former reported experiencing greater care-giving difficulties, more child-related stress and also more parent-related stress than parents with a typically developing child. Importantly, this study included the views of both mothers and fathers, with inclusion of fathers being a positive factor. However all the families who took part were two parent families, which raises the question of how representative this is of the general population?

### *3.1 Parental mental health*

The question of whether the additional stresses which parents of a child with a learning disability experience, impact on their psychological well-being has been frequently considered in the literature. As highlighted earlier, Glidden and Schoolcraft (2003) found that, at the time of diagnosis, birth mothers reported clinically significant levels of depression. However, this was a longitudinal study and they found that, following this initial period of shock and low mood, mothers reported low levels of depression that were not clinically significant. Importantly, Glidden and Schoolcraft (2003) found the biggest predictor of maternal depression to be the personality trait of neuroticism for both birth and adoptive mothers. This suggests that a mother's general tendency towards mental health has a greater impact on whether she experiences depression than any difficulties her child may have.

Gowen, Johnson-Martin, Goldman & Appelbaum, (1989) compared mothers of children with and without a learning disability and found them not to differ on measures of maternal depression or feelings of parenting competence. There

were, however, different predictors of these factors for the two groups of mothers; for those whose child had a learning disability, care-giving difficulty predicted depression and quality of family relations predicted feelings of parenting competence. For the mothers of children without a learning disability, child irritability and quality of family relations predicted both feelings of depression and parenting competence. This was a longitudinal study providing information about maternal depression over time, and thus was more likely to give an accurate picture than a measure taken at a single time point.

Harris and McHale (1989) also compared mothers of children with and without a learning disability and, in particular, looked at family life problems, daily care-giving activities and psychological well-being. They found no difference in overall well-being between the two groups. They did, however, find differences in family problems between the two groups, with mothers of children with a learning disability reporting child welfare issues and restrictive time demands as the most intense family problems. A strength of this study is the close matching of the two groups of parents on age and gender of child along with socio-economic factors. This adds weight to their suggestion that it is having a child with a learning disability that impacts on family problems rather than demographic factors.

The research cited above indicates that there is not a straightforward relationship between having a child with a learning disability, stress and parental psychological difficulties. This raises the question of what helps these

families to manage and cope with the additional stresses they experience?

Further what impacts on this stress both positively and negatively?

### *3.2 Factors mediating the stress experienced by families with a child with a learning disability*

The stress experienced by families with a child with a learning disability is affected by numerous different factors. Frey, Greenberg & Fewell, (1989) examined the relationships of child characteristics, family social network, parent belief systems and coping styles to parental stress in parents of children with a learning disability. They broke stress down into three component parts of parenting stress, psychological distress and family adjustment and found that different factors influenced these components for mothers and fathers. For example, both mother and father parental stress were related to child characteristics, and child characteristics were also related to psychological distress in fathers but there was no such association found with mothers' psychological distress. Thus whilst there may be similarities in factors impacting on stress and psychological distress in mothers and fathers, some factors may play more of a role in one parent's stress than the other's stress. The roles of coping style and belief system were also found to be important in predicating stress in families.

It is noteworthy that Frey et al. (1989) go on to link their findings to possible interventions, suggesting that knowing the key factors in a family's stress could guide intervention. For example if parental coping style is found to be

associated with the family experiencing greater stress then interventions focussed on promoting alternative coping strategies might be appropriate.

Thus there are several factors which can impact on the stress families with a child with a learning disability can experience which can be important to consider if services are to provide the best possible support.

### *3.21 Child factors*

These are factors relating directly to the child such as the age of the child, physical disabilities, severity of the learning disability, communication skills and their specific diagnosis. These factors have been shown in the literature to contribute to and impact on parental stress.

#### *3.211 The nature of a child's difficulties as a factor in parental stress*

Hodapp, Fidler & Smith, (1998) highlight that a child's specific type of learning disability could impact on parental stress, as different aetiologies can predispose children to different behaviours and skill levels. When studying families who had a child with Smith-Magenis syndrome, Hodapp et al. (1998) found that certain child factors did impact on family stress. In particular, the degree of impairment in socialisation, as measured by the Vineland Adaptive Behaviour Scale, (Sparrow et al., 1984) related to overall stress and parent-family problems. They also found pessimism scores were higher in families whose child had a higher maladaptive behaviour score. Although the Smith-Magenis

syndrome population is relatively small, it is important that the experiences of parents whose children have different and rarer diagnoses are considered.

Behaviour problems have also been found to predict mothers' perceived negative impact of young adults with a learning disability on the family, (McIntyre, Blacher & Baker, 2002). The severity of an individuals' disability would intuitively seem important when considering the impact on parental stress and Friedrich, Wiltturner & Cohen, (1985) did find both severity of the disability and behaviour problems to be related directly to the parent and family problems subscale of the Questionnaire on Resources and Stress (Friedrich, Greenberg & Crnic, 1983).

Beck, Hastings & Daley, (2004) looked at both pro-social and anti-social behaviour as predictors of maternal stress in families with a child with a learning disability. They found that a child's pro-social behaviour was a negative predictor of maternal stress, whereas behaviour problems were a positive predictor of stress. Such studies are important, as consideration of positive and negative factors allows a more balanced view on the factors that can impact on maternal stress.

Hoare, Harris, Jackson & Kerley, (1998) conducted a community survey of families who had a child with a severe learning disability looking at adjustment, carer distress and use of respite. Carer distress was measured using a questionnaire assessing psychiatric morbidity in community samples. They found that higher ratings on this questionnaire were significantly associated with

certain child characteristics including the physical dependency of the child and the child's sleep difficulties. They also found higher ratings on this measure for carers of children who were unable to communicate their needs compared with those whose children had some communication skills. This study is particularly relevant to the current one as it uses a Scottish sample drawn from special schools. Frey et al. (1989) also found that parents reported greater stress when their child had lower communication skills. Interestingly they also found that gender played a role with boys being experienced as more stressful. Kwai-sang Yau and Li-Tsang (1999) conducted a systematic review of the literature on adjustment and adaptation of parents with a child with a learning disability. In their exploration of the literature on child factors they found that level of impairment, particularly with regard to communication, was associated with higher parental stress. The gender of the child was also found to be relevant with boys being viewed as more stressful than girls.

Thus the nature of a child's difficulties, particularly their manifestation can impact on the stress experienced by parents. Behaviour problems appear to impact on parents both directly through posing management difficulties and indirectly by impacting on the likelihood of others getting involved in care and also by affecting a parent's perception of their caregiving situation. Difficulties in communication have also been found to be related to higher stress levels along with greater physical dependency of the child. The nature of a child's difficulties is undoubtedly related to their diagnosis with different diagnosis being associated with different presentations.



### *3.212 The impact of the specific diagnosis on parental stress*

The child's specific diagnosis can also be viewed as a factor in the stress experienced by parents and there is some literature examining differing experiences of stress in parents whose children have a learning disability, but different diagnoses. Sanders and Morgan (1997) compared parents' perception of family stress and adjustment in families with a child with Down syndrome, Autism or typical development. They found that parents of children with Down syndrome or Autism reported greater stress than those of typically developing children. In addition, parents whose child had Autism reported higher stress than parents of children with Down syndrome. Parents of children with Autism were found to perceive more stress related to parental and family problems than the other two groups of parents, which were particularly associated with demands on time and opportunity for family activities. Sanders and Morgan (1997) also found that a significant stressor for parents of children with a learning disability is worry about the future for their child, with parents of children with Down syndrome or Autism reporting higher pessimism for their child's future than parents of typically developing children. However, there was no difference in pessimism between parents of children with Down syndrome or Autism. The research by Sanders and Morgan (1997) is important in illustrating the impact that diagnosis can have on parental stress. While they focus on two conditions that are closely associated with having a learning disability, there are many others that are little studied.

Cahill and Glidden (1996) investigated the influence of child diagnosis with particular reference to Down syndrome compared to other disabilities. They

challenge the view that children with Down syndrome have a pleasant temperament and are easier to raise than children with other disabilities. They report that, when the existing literature is examined, comparisons between families with a child with Down syndrome and families with a child with a different cause of learning disability are often made without controlling for factors such as child's level of functioning, age, marital status and family income which can all play a role in the stress experienced by families. They found that when they compared parents whose child had Down syndrome with parents of a child with a different cause of learning disability and matched the groups on the factors of child's level of functioning, child age, marital status and family income the differences in stress between the two groups were not found to be significant. They suggest that whilst the positive impact and stresses of having a child with a learning disability can manifest in different ways depending on a child's diagnosis, the overall effect on family and individual functioning can be similar.

Abbeduto, Seltzer, Shattuck, Krauss, Orsmond and Murphy (2004) also compared families who had children with different diagnoses but could all be considered to have a learning disability. They suggest that whilst the diagnosis itself is unlikely to make a difference, different diagnoses are likely to cover different behavioural challenges and these may impact on family stress. They also suggest that the different diagnoses and the processes involved in making them can have an impact on families. They use the example of Down syndrome where a diagnosis is made early in a child's life, with a clear explanation of the cause of the difficulties. In addition, there is considerable knowledge on the

likely development and prospects for the future of the child. They highlight the contrast with Autism, where the diagnosis is behavioural and unlikely to be given before the child is two. There is also less agreement about the cause of the difficulties and likely future development.

Abbeduto et al. (2004) compared well-being and coping in mothers of adolescents with Down syndrome, Autism or Fragile X syndrome. As in the work by Cahill and Glidden (1996) described above, Abbeduto et al. (2004) found that initially there did appear to be significant differences, with mothers of adolescents with Down syndrome reporting less pessimism and lower depression scores than the other two groups of mothers. However once demographic characteristics, behavioural symptoms and maternal coping patterns were controlled for, there were no significant group differences on measures of pessimism or depression. One significant difference remained, even when these factors were controlled for, with mothers of adolescents with Autism reporting less reciprocated feelings of closeness with their adolescent.

Abbeduto et al. (2004) suggest that, as the adolescents with Autism had more behavioural problems when compared with those with Down syndrome, it is likely that some of the differences found before controlling for various factors, were due to the differing care-giving challenges posed by the different diagnoses of the children. It is important to note that Abbeduto et al. (2004) drew their data from two existing studies and this resulted in very different numbers in the different diagnostic groups, which may have implications for how representative each group was. Further, when considering difficult

behaviour this was assessed using a measure of autistic behaviours, thus different behaviour problems and their impact were not considered. For example there may be behaviour difficulties such as skin picking or pica that would not appear on a measure of autistic behaviours, yet could still be a source of stress for parents.

A particularly interesting finding was that of Eisenhower, Baker and Blacher (2005), who compared behaviour problems and maternal well-being in different syndrome specific groups of children with a learning disability, including a control group of typically developing children. Eisenhower et al. (2005) found that mothers of children with Autism reported more stress than all the other groups. Importantly, even when differences in behaviour problems and cognitive level were controlled for, they still found that the specific syndrome of the child contributed to maternal stress. This suggests that there may be differences between diagnoses other than behaviour and cognitive ability that play a role in parental stress.

Whilst one must be careful when comparing diagnostic groups to control for certain social factors, it is important to note that the different diagnoses do describe different patterns of difficulties which will impact on parental stress. This goes back to Abbeduto et al.'s (2004) earlier point that it is not necessarily the diagnosis itself but what that diagnosis means that can impact on stress. Therefore diagnoses that are linked to more problematic behavioural difficulties such as Autistic Spectrum Disorder may be associated with higher levels of parental stress, (Abbeduto et al. 2004). There may also be factors other than

behavioural manifestations of the different diagnoses that impact on parental stress, such as associated health complications e.g. heart abnormalities in people with Down syndrome. It is also important to consider the impact of not having a specific diagnosis. While a parent of a child with Autistic Spectrum Disorder may experience higher stress due to behavioural difficulties associated with the condition, having a diagnosis also means that they may have access to information about the likely difficulties their child may have. This may prepare them and allow them to develop appropriate coping strategies. Where there is no such specific diagnosis, parents are unlikely to have access to the same level of information regarding the difficulties their child may be likely to experience and thus may be less able to prepare themselves for the challenges ahead.

### *3.22 Parent factors*

There are also factors relating to the parents of children with a learning disability which impact on the stress they experience. These factors include the parents' beliefs and cognitions about their child and the stress they experience, different coping styles, the strength of the parents' relationship and socio-economic factors such as education level and family income.

#### *3.221 Parental beliefs, cognitions and coping strategies*

The beliefs of parents about their care giving situation and their child's difficulties along with coping strategies have been found to impact on parental stress in families with a child with a learning disability. Essex, Seltzer & Krauss, (1999) in a longitudinal study with a large sample, examined the effects

of different coping strategies on parents' psychological well-being who had adult children with a learning disability. They found that, for mothers, increased use of problem-solving type coping strategies buffered the effects of care-giving stress on their psychological well-being, however this was not the case for fathers. Conversely, Rousey, Best & Blacher, (1992) found that there were minimal differences between mothers and fathers on perceptions of stress and coping with children with severe disabilities.

In a comparison of coping styles of mothers of adult children with either a learning disability or a mental illness Kim, Greenberg, Seltzer & Krauss, (2003) found that problem-focussed coping was associated with better psychological outcomes in a large sample of mothers. Furthermore an increase in emotion-focussed coping was associated with higher depression levels and subjective burden. For the mothers of children with a learning disability an increase in problem-focussed coping was associated with lower levels of depression and subjective burden and improved relationships with their child. Frey et al. (1989) also found problem-focussed coping to be associated with less parenting stress and psychological distress, with avoidance as a negative coping style being associated with greater psychological distress.

Frey et al. (1989) noted that parental beliefs were the most powerful factor associated with parental outcome. They found that parents, who rated their own coping efficacy as high, experienced less stress and better coping. High personal control was also associated with better outcomes for parents, with low personal control being associated with psychological distress and parenting

stress. However Abbeduto et al. (2004) in their comparison of psychological well-being and coping in mothers of children with Down syndrome, Autism or Fragile X, found that there were no buffering effects of problem-focussed coping strategies. They do suggest various reasons for this finding, including small sample size and also the fact that, as the behavioural difficulties of children with Autism and Fragile X can be unpredictable, it can be difficult to use focused problem oriented strategies when the problem can be constantly changing.

Hassall, Rose & McDonald, (2005) investigated the effects of parent cognitions in parenting stress, with a particular focus on parenting self-esteem, including efficacy, satisfaction and parental locus of control. They found relationships between mothers' higher parenting self-esteem and lower parenting stress, with a particularly strong relationship between parenting satisfaction and parenting stress. They also noted that an internal locus of control was associated with lower parenting stress levels. Hassall et al. (2005) recruited their sample through special schools which should provide relatively representative findings, although participants were largely middle class. In an earlier study Friedrich et al. (1985) also found locus of control to be an important factor with mothers who considered themselves capable and able to make changes reporting fewer difficulties.

Thus belief systems, perceptions of the situation, cognitions and coping styles all appear to impact on caregiver stress, however the degree to which they impact can vary with gender and no doubt from individual to individual.



### *3.222 Differences in mothers' and fathers' stress*

It appears that different factors can play a role in parental stress for mothers and fathers, Krauss (1993), using detailed data from longitudinal study, found that for mothers the personal impact of parenting a child with a learning disability, such as parental mental health, social isolation and role restrictions, gave rise to greater stress. However, child factors such as the child's behaviour and temperament were found to be related to higher stress in fathers. Saloviita, Italinna & Leinonen, (2003), using a component analysis, found that the most important predictor of parental stress was a negative definition of the situation. Furthermore, for mothers this negative definition was associated with behavioural problems of the child, whereas for fathers it was related to experiences of social acceptance of the child. However, once again single-parent families were not included in the research and yet it is this group that may be more vulnerable to stress due to being solely responsible for parenting.

Bristol, Gallagher & Schopler, (1988) found that fathers were less involved in the care of their disabled child when that child had greater language difficulties and behavioural issues. In such a situation the child's difficulties not only directly affect the father, but through him being less involved, are likely to affect maternal stress because the mother experiences less support and increased caregiving responsibilities.

In a comparison of fathers of a child with Down syndrome and fathers of children with other types of learning disability, Ricci and Hodapp (2003) found that there were several child factors that were related to stress. They noted that



both mothers and fathers of children with Down syndrome rated their child as having more positive personality traits and less maladaptive behaviour than parents of children with other types of learning disability. Interestingly it was fathers of children with Down syndrome who reported less stress in parenting, less overall stress and less stress related to their child's acceptability, adaptability and level of demands than fathers of children with other types of learning disability. This suggests that child factors do play a role in the stress experienced by fathers of children with a learning disability. Such studies which focus solely on fathers' experiences are rare and yet they are important if the needs of a whole family are to be successfully met.

### *3.23 Social factors*

The importance of social factors in families with a child with a learning disability is raised by Emerson (2003), who considers these in relation to mental health and the psychological impact of the child's difficulties. Emerson (2003) found that families supporting a child with a learning disability were significantly disadvantaged economically when compared to families whose children did not have a disability. Furthermore, he found that poverty was associated with maternal mental health problems. Once social factors were accounted for, having a child with a learning disability marginally reduced the chance of mothers having mental health problems.

The role of education level of parents can also be seen to link to parental stress and coping abilities, with those with a higher level of education showing less stress. Hodapp et al. (1998) found maternal education level to be associated

with parent and family problems, pessimism and overall stress, with those with higher education levels showing better outcomes. Kwai-sang Yau and Li-Tsang (1999), in their systematic review of the literature on adjustment and adaptation in parents of children with a learning disability, found evidence that parents with higher education levels were more able to cope with their child's difficulties. They also highlight that parental education level is likely to influence family income and socio-economic status which again influences parental coping as noted above by Emerson (2003).

### *3.3 The role of support and information in the stress experienced by families*

Intuitively one would expect support and information provided to families to have a mediating effect on the stress experienced by families with a child with a learning disability. In particular having a network of supports that can provide emotional and practical help would seem likely to be beneficial to families with high levels of caregiving demands.

#### *3.31 The effect of support on stress*

Hassall et al. (2005) found there to be a strong correlation between family support and parenting stress, with mothers who had greater levels of social support experiencing less parenting stress. A particularly interesting finding was that it was the perceived helpfulness of the support, rather than the number of supports which impacted on parenting stress. Similarly, Frey et al. (1989) found that social network was associated with family adjustment and further, for mothers, it was the amount of assistance provided by the support network that

was important. This again suggests it is the nature of the support, rather than number of supports, that is important.

It is also important to consider how those involved in supporting the family can also be a source of stress. Frey et al. (1989) found that, for fathers, family criticism accounted for a large proportion of the variance in family adjustment and was associated with parental stress. This is supported by Hastings, Thomas & Delwiche (2002) who examined the effects of grandparent support in families with a child with Down syndrome. They found that, whilst grandparent support was an important factor in stress, with support being associated with lower levels of stress, conflict between parents and grandparents was associated with increased parental stress. Furthermore, these two factors impacted independently on parental stress, thus it is possible for someone to be both a source of support and a source of stress to a family with a child with a learning disability. Hastings et al. (2002b) do highlight that they did have a low response rate from participants and thus the sample might not be representative. However they also point out that this is a little studied area and their findings do provide the basis for further research. It also highlights the importance of family members in providing parents with support and prompts the question what other sources of support are available to families?

### *3.32 Informal support*

Hodapp, Dykens & Masino (1997) examined sources of support for families with a child with Prader-Willi syndrome. They found that the majority of those providing support were family members, and friends were also a frequent source

of support. Interestingly professionals formed only a very small part of families' support networks, with 67% of the families not listing any professionals amongst their support network. Hodapp et al. (1997) noted this as a surprising result due to the high level of needs of children with Prader-Willi syndrome and the high levels of stress such families are under. This is particularly surprising when one considers their sample was drawn from parent groups, suggesting these are likely to be families who are more able to seek help. It thus raises the question of whether professionals are providing or indeed offering any valuable support to this group of families.

A further consideration is that different diagnoses may affect the support available from family and friends. If a child has a diagnosis such as Down syndrome it is widely understood that the child has a disability and the parents are likely to need support in caring for the child. However understanding of learning disability in the general public is variable. Aminidav and Weller (1995) found that understanding and knowledge of the term mental retardation in Israel varied with country of origin and social class. Antonak, Fiedler and Mulick (1989) conducted a study in the USA examining peoples understanding of the term mental retardation in relation to agreement with common misconceptions. The misconceptions were statements such as 'mental retardation is always inherited', 'mental retardation is a mental illness' and 'mentally retarded people are equally impaired'. Antonak et al. (1989) found that endorsement of misconceptions varied with professional training, occupation and contact with people with mental retardation. Thus the

understanding and support available to families may depend on the cultural, occupational and social background of the person offering support.

### *3.33 Professional services support*

In a later study, Hodapp et al. (1998) examined stress in a different diagnostic group, that of Smith-Magenis syndrome. They found that for this group of parents, support from family, friends and professionals was found to be helpful and a moderator in stress. In particular they found that the number of family friends was the strongest lone predictor of lower stress levels in families. In contrast to the families of children with Prader-Willi syndrome (Hodapp et al., 1997), 76% of the families of children with Smith Magenis syndrome included one or more professionals in their list of supporters. Again the sample was drawn from a parent group, suggesting that these are likely to be families who actively seek support. This research indicates that diagnosis may influence the support available from professionals.

Levy, Rimmerman, Botuck, Ardito, Freeman and Levy, (1996) examined the support network of mothers of people with a learning disability (both children and adults). They found that mothers relied more on professional supports than support from family and friends, furthermore mothers frequently rated the support they did receive from family members as unhelpful. Whereas professional supports were rated as helpful by the vast majority of mothers. This may be linked to professional services having a greater understanding of learning disability as suggested by the results of Antonak et al. (1989) and how this manifests as support needs.

Donovan (1988) examined family stress and coping in families of adolescents with a learning disability. She found that maternal coping styles were characterized by a reliance on professionals and support from outside the family. Mothers also found interventions that aimed to mobilise family resources, define the situation more optimistically and maintain their own psychological well-being less helpful and used these less often. However it is not stated what exactly such interventions involve. Donovan (1988) suggests that these findings are due to mothers seeking professional support when demands exceed family resources. Thus professionals may only become part of a support network at times of difficulty.

Further to the suggestion that families seek help from professionals only at times of particular difficulty, there is some literature looking at when families use respite care. Withers and Bennett (2003) illustrated in a case study the potential barriers to useful support in the form of respite by professionals who held the belief that too much respite was harmful, despite parents caring for a child with severe difficulties and a very high level of care needs. Hoare et al. (1998) found that respite use was associated with high levels of carer distress, once again suggesting that families only seek such help at times of great need. Though alternatively perhaps families can only access professional support when there is great need.

### *3.34 Information and stress*

There has been little research on the provision of information to parents and the potential impact this may have on stress. Leino-Kilpi, Iire, Suominen, Vuorenheimo and Valimaki (1993) in a review of information provision to those with physical health problems, found evidence that provision of information helped patients cope with health difficulties and stress. Within the learning disability population Quine and Rutter (1994) found that the majority of parents wanted more information than they had received and found it difficult to gain information from professionals. However it is yet to be found whether difficulties in accessing information has a relationship with parental stress in families with a child with a learning disability.

### *Section three summary*

Parents caring for a child with a learning disability have been found to experience higher stress levels than parents of children without a learning disability, (Dyson, 1993, Roach et al. 1999). However, whilst there are some signs of depression amongst mothers at the time of diagnosis, these are generally not long-term and studies reporting clinical signs of depression in mothers of children with a learning disability are infrequent (Glidden & Schoolcraft, 2003). There are several factors that impact on parental stress in families with a child with a learning disability. The nature of the child's difficulties have been shown to impact on stress, particularly with regard to difficult behaviour being associated with higher levels of parental stress, (McIntyre et al., 2002, Beck et al., 2004). Different diagnoses of children have also been associated with different levels of stress, with the diagnosis of ASD

often found to be associated with higher parental stress than Down syndrome, (Sanders & Morgan, 1997, Abbeduto et al., 2004). This may not, however, relate to the diagnosis per se, rather it may be that different diagnoses have different behavioural manifestations, with ASD in particular, being associated with difficult behaviour, (Abbeduto et al. 2004).

There are also parent factors that can impact on the family stress. Parental coping style has been found to be an important factor, with greater use of problem-solving focussed coping being associated with better outcomes, (Essex et al., 1999, Kim et al., 2003). Parental locus of control and particularly parental self-esteem have also been found to impact on parental stress, with parents with higher levels of self-esteem and a more internal locus of control experiencing lower levels of stress (Hassall et al., 2005). Higher parental education levels have also been found to be associated with better coping, (Hodapp et al., 1998, Kwai-Sang Yau & Li-Tsang, 1999).

Support can play a key role in alleviating some of the stress families with a child with a learning disability experience. The quality and nature of support has been found to be more important than the number of supports, (Hassall et al., 2005). The main sources of support for families varies with some studies finding family and friends to be the most frequent sources of support, (Hodapp et al., 1997). However there has also been found to be a reliance on and valuing of professional services as support (Levy et al., 1996, Hodapp et al., 1998). There has been little research on the impact provision of information has on





parental stress, despite parents often wanting more information than they have received and difficulties accessing information (Quine & Rutter, 1994).

#### **Section four: Introduction summary**

The term 'learning disability' is the most widely used and accepted term in UK health and social care settings. The BPS (2000) set out three core criteria for learning disability; impairment of intellectual functioning, impairment of adaptive social/functioning and onset before adulthood. Such a definition is generally agreed across different professional bodies including those in North America who use the term mental retardation. Assessing these three criteria is not without its problems, particularly with regard to adaptive functioning which is difficult to measure. Furthermore, there is debate around who actually meets all three criteria, who needs and who receives learning disability services, (Whittaker, 2004). There are many different causes of learning disability. These include pre-natal causes such as chromosomal abnormalities resulting in diagnoses such as Down syndrome, peri-natal causes such as hypoxia at birth leading to brain damage, and post-natal causes such as infections like meningitis. There are also disorders that are associated with learning disability but as yet have no known cause such as Autistic Spectrum Disorder. There are also a significant proportion of people with a learning disability for whom there is no known cause of their difficulties, (Wellesley et al. 1991).

Despite the term learning disability being the most frequently used and that which is referred to by government health and social care documents, it is not

always widely understood. Even professionals working in the field of learning disability can have little knowledge of the three core criteria for a learning disability diagnosis, (McKenzie et al. 1999a). Other terms such as learning difficulties and intellectual disabilities are used interchangeably with learning disability. The confusion of terms is particularly evident when education services are involved. Education services do not refer to learning disability and use a variety of other labels or choose not to use any diagnostic labels. The Education (Additional Support for Learning) (Scotland) Act 2004 does not use the term learning disability at all, yet it is through this Act that parents have the legal basis to access services for their child with a learning disability. It does raise the question of whether, if a child is never referred to as having a learning disability will learning disability services be seen as relevant, referred to or even accessible.

For families, receiving the news that their child has a learning disability is often experienced as distressing and results in feelings of shock and a grief like reaction, (Rendall, 1997, Maxwell & Barr, 2003). There is considerable dissatisfaction amongst parents with the way the diagnostic process is handled. Furthermore dissatisfaction is higher when there is a considerable wait, at times years, before a diagnosis is made; such delays are more common when the diagnosis is that of learning disability and not a more specific syndrome or disorder, (Quine & Rutter, 1994). Quine and Rutter (1994) found that a large proportion of their sample reported that it was difficult to get information about their child's condition and nearly three quarters wanted more information than they had received. One can imagine that it would be harder to access

information about a child's condition when there is only a broad diagnosis of learning disability, which doesn't tell a parent a great deal and often professionals are unsure of how the difficulties will manifest and develop. Whereas for those with a more specific diagnosis there is often a clearer picture of how their difficulties will develop and possible future problems that can be accessed through disorder specific organisations, such as the National Autistic Society.

Parents with a child with a learning disability have been found to experience increased stress in relation to their child compared to parents of children without disability (Dyson, 1993, Roach et al. 1999). There are several factors that impact on the stress parents of a child with a learning disability experience, including child factors such as level of problem behaviour and communication impairment, (Beck et al., 2004, Frey et al., 1989, Kwai-sang Yau & Li-Tsang, 1999). Different diagnoses have also been found to be associated with different levels of parental stress. The diagnosis of Autism has been found to be associated with higher parental stress than that of Down syndrome and Fragile X syndrome, (Sanders & Morgan, 1997, Abbeduto et al., 2004). It has been suggested that it is not necessarily the diagnosis itself, but how the difficulties manifest that differs across diagnoses and it is these differences that can impact on parental stress, (Abbeduto et al., 2004, Cahill & Glidden, 1996).

Parental coping style and cognitions have also been found to be associated with parental stress levels, with problem-solving focussed coping styles and a more internal locus of control associated with better outcomes (Essex et al., 1999,

Kim et al., 2003, Hassall et al., 2005). The support families have access to can have a positive effect on parental stress. Importantly it is the quality and nature of the support rather than number of supports which impacts on stress (Hassall et al., 2005, Frey et al., 1989). Family members and friends can be the main sources of support available to families with a child with a learning disability (Hodapp et al., 1997, Hodapp et al., 1998). Professional services as sources of support are also utilised and valued by families with children with a learning disability, (Levy et al., 1996, Hodapp et al., 1998). The use of professional services can be associated with higher carer distress and some authors suggest that help is sought when difficulties become too severe or complex for family supports to cope with, (Donovan, 1988, Hoare et al., 1998). There is the possibility that services and professionals are more available for support when difficulties are severe and families are really struggling. There has been little research on the impact of information provision on parental stress, despite parents reporting difficulties gaining and wanting more information about their child's difficulties, (Quine & Rutter, 1994).

#### **4.1 Research with families with a child with a learning disability**

The research cited in the introduction was systematically reviewed for methodological strengths and weaknesses, see Appendix II. A common methodological weakness was small sample size. This may be due to the fact that such families are experiencing the stress and lack of support which researchers are investigating and as a result participation in research projects is not a priority for these families. However recruitment amongst this population

remains a difficulty that needs to be considered if research is to truly reflect the experiences of this population.

### **Section five: Thesis Rationale/Aims**

With the confusion around terminology and lack of knowledge amongst professionals regarding the term learning disability (McKenzie et al., 1999), it is reasonable to question what information parents of a child with a learning disability receive and what their understanding is of the diagnosis. The fact that the term learning disability is rarely used in education settings indicates that the child is likely to be given a different label, potentially adding to parental confusion. When a child is given a more specific diagnosis, such as Down syndrome, professionals are likely to have clearer knowledge of what this diagnosis means for the child and as a result provide parents with more information. A specific diagnosis also means that parents can turn to diagnosis specific support organisations for information and advice. This option may be less available to those parents who have a child without a specific diagnosis. There is also perhaps less understanding amongst the general public regarding the term learning disability, (Antonak et al., 1989). This suggests that parents whose child has a diagnosis of learning disability, rather than a more specific diagnosis, may have received less information and support from professionals and may be less likely to be able to access alternative sources. Will such families, therefore, experience higher stress levels?

The current study aims to investigate whether the following varies according to whether a child receives a diagnosis of 'learning disability' or a more specific diagnosis:

- ❖ amount of information parents receive about their child's difficulties,
- ❖ parental access to support
- ❖ levels of parental stress

In relation to support this study also looks at the sources of support, in particular the use of support organisations and professional services. Whether there is a relationship between greater information and support and levels of parental stress in families with a child with a learning disability is also considered.

## **5.1 Hypotheses**

### **Hypothesis one**

Parents whose child has a diagnosis of 'learning disability' alone will have received less information about their child's difficulties than parents whose child has a more specific diagnosis.

### **Hypothesis two**

Parents of children with a non specific 'learning disability' diagnosis will have less access to support organisations than parents of children with a more specific diagnosis.

### **Hypothesis Three**

Parents of children with a specific learning disability diagnosis will have more access to professional support than parents of children with a non-specific learning disability diagnosis.

### **Hypothesis four**

Parents of children with a non specific 'learning disability' diagnosis will experience greater levels of stress than parents of children with a more specific diagnosis.

### **Hypothesis Five**

Lower levels of information and support will be associated with higher levels of stress in parents of children with a learning disability.

## **Methods**

### **Systematic Literature Review**

A literature review was carried out using the OVID databases PsychInfo and Medline. A search of relevant policy documents was conducted via the Scottish Executive website. The search terms used were learning disability, mental retardation, parents, stress, support, diagnosis, information and children. The search criteria were English language and publication dates 1966-2006. Papers were included if they were from a peer-reviewed journal and were based on a learning disability population original research study or a review paper. Articles were excluded if they were from North America and used the term Learning Disability to refer to learning difficulties or the parents involved in the research had a Learning Disability themselves.

In addition papers were reviewed with regard to the area investigated, outcome of the research, methodological strengths and weaknesses. An effect size was calculated where possible for individual papers. See Appendix II for systematic review table.

### **Study design**

The research was a questionnaire based quantitative design, which examined both within and between group differences.



## **Procedure**

Following receipt of ethical approval from the education department of the local councils, head teachers of twelve special schools in these areas were contacted by letter. The letters explained the nature of the research and enclosed a brief outline of the research methodology, the parental information sheet, consent form and three questionnaires for their consideration. This was then followed up by a telephone call asking whether the research information had been received and whether they were happy for the school to take part in the research. Two special schools from each of the three council areas agreed to take part. The head teacher of the special schools in one area was also head of inclusion support and was keen that these parents were also included, as, due to the inclusion policy of that area, there were many children with a learning disability in mainstream school. The inclusion support service for this particular area was, therefore, also included.

Following head teacher agreement, questionnaire packs were delivered to the participating schools. The pack contained an information sheet, consent forms, three questionnaires and return envelope for each family with a child attending one of the six special schools or inclusion support service. The questionnaire packs were then distributed by schools by sending them home with pupils, as is routine for communication between school and home. The parental information sheet included contact details for the researcher should parents have any questions regarding the research and they were also informed they could contact the researcher if they wanted help to complete the questionnaires. All packs included a stamped addressed envelope for returning the questionnaires. None

of the parents contacted the researcher requesting further information or requesting help with completion of the questionnaires.

## **Ethics**

Ethical approval was sought from the Education department of four local councils. Three councils gave permission for the research to be carried out in special schools and provision in their area. Two of the areas were happy to receive request for ethical approval via letter, one of these requested further details about the research and one council had a research pro-forma to complete. One council rejected ethical approval as they felt there had been too much research conducted in the special schools in that area at the time of the study. Ethical approval was not sought from an NHS ethics committee as there was no involvement of NHS patients, services or premises.

The main ethical issues of the study were around identification of participants. In order to maintain anonymity of participants and also comply with Education department data protection policy, the questionnaire packs were not individually addressed and the researcher did not have any access to children or parent details. The questionnaire packs were simply addressed to parent/guardian and distributed by school staff. A potential ethical issue was that completing the questionnaires might raise questions for parents around the issue of diagnosis and may also cause distress. The information sheet invited participants to contact the researcher if they had any questions relating to the research. If a parent did contact the researcher regarding issues raised by the questionnaires, that were not simple queries about the research or completing the

questionnaires, but rather a more personal impact of the research, the researcher would have directed them to a relevant health or education professional equipped to deal with their query rather than attempt to deal with the issues herself. However none of the participants contacted the researcher.

## **Participants**

The participants were parents of children with a learning disability attending six special schools in three council areas in central Scotland. Parents of children receiving inclusion support services in mainstream school were also included in one of the council areas. A total of 273 parents were invited to participate. 47 parents returned the completed questionnaires and consent forms, producing a response rate of 17.2%. The total sample size was therefore 47 with 24 parents having a child with a non-specific learning disability diagnosis and 23 parents having a child with a more specific diagnosis.

## **Measures**

### *Demographic, diagnosis and information questionnaire*

The questionnaire was designed to obtain the following information: demographic; diagnostic; source and amount of, and satisfaction with information received from professionals. As such, it is not a standardised measure; however it was devised with the principle in mind that good questionnaires are objective, reliable and valid and used with the group it was devised for (Dickens & Stallard, 1987).

The questionnaire contained questions relating to the following:

- ❖ The number and type of terms used to refer to their child's difficulty
- ❖ parents' understanding of the diagnosis their child had received
- ❖ the age of the child at diagnosis
- ❖ who had given the diagnosis.
- ❖ whether parents have received information as their child has developed, once at the time of diagnosis or not received any information.
- ❖ The source/sources of information.

(See Appendix III for a copy of the questionnaire)

For each potential source of information parents are asked to rate on a six-point likert scale, from none to a lot, how much information they have received from that source. They are also asked to rate on a six-point likert scale how satisfied, from dissatisfied to very satisfied, they have been with information they have received from that source.

### *Scoring system*

The question 'does your child have a specific diagnosis?' has yes/no tick boxes and a space to specify the diagnosis. Children were rated as having a specific diagnosis if their parents ticked yes and the diagnosis specified was directly related to having a learning disability. If the diagnosis was not directly related to having a learning disability, but sometimes present in those with a learning disability e.g. a sensory impairment, the child was not counted as having a specific diagnosis. The other questions relating to diagnosis are straight forward tick boxes, with the opportunity to tick more than one box. These

questions were scored in terms of whether or not each of the options had been ticked. The exception was one question that would yield qualitative answers to be analysed separately. The questions relating to amount of, and satisfaction with, information received from professionals involve Likert scales where numbers were circled and thus provided numerical scores.

### *Objectivity*

Objectivity indicates that a measure is as unbiased by personal opinion and emotions as possible. The questionnaire items in this study were informed by research as outlined in the introduction, for example, Quine & Rutter (1994) who found that the majority of parents had found it difficult to obtain information about their child's difficulties and frequently wanted more information than they had received from professionals. The questionnaire was designed to target the areas of interest of the study and was also influenced by the views of clinical psychologists working in this specialty. As such, the questionnaire items were not influenced by the personal opinions of the researcher.

### *Validity*

There are several forms of validity, many of which are not applicable to the questionnaire devised for the current study. For example it was not relevant to examine criterion related validity, as there was no other validated measure which addressed the same areas of interest (Crookes & Davies, 1998).

Similarly, construct validity, that is the agreement between a theoretical concept and a specific measure, could not be addressed in relation to this questionnaire.

### *Content Validity*

This is the subjective judgement of whether the questionnaire items are relevant to the area of interest (Eby, 1993). This was met by ensuring that the questionnaire items were informed by or directly related to the relevant research literature. For example parents were asked if their child had a specific diagnosis and two examples were given. The research literature has found that, for up to 50% of those with a learning disability there is no known cause and no more specific diagnosis than learning disability (McLaren & Bryson, 1987). The examples were selected to reflect the very different specific diagnoses that can be associated with a learning disability. Chromosomal abnormalities account for up 17% of those with a learning disability and Down syndrome makes up 90% of chromosomal abnormalities related to learning disability (Wellesley et al., 1991). Furthermore people with Down syndrome are easily recognised by the public as having a disability. Thus Down syndrome was selected as an example of a common and well-known cause of learning disability. Autistic Spectrum Disorder was selected as it reflects a very different population as there is no known cause of ASD and individuals with ASD are less easily recognised as having a learning disability by the general public. The items also reflect the clinical judgement of professionals working in the specialty of learning disability.

### *Face validity*

This assesses whether a questionnaire measures what it claims to, by reflecting the current knowledge base (Eby, 1993, Gross, 1996). For this questionnaire, face validity was closely related to content validity as it was established by gaining the views of professionals working in the specialty regarding whether they felt the questions reflected the area of interest. The questionnaire was amended in light of comments from the different professionals, until there was a consensus that all items had face validity.

### *Social Validity*

Here the questionnaire must address areas of relevance to the group it is being used with (Stanley & Roy, 1988). The current questionnaire was developed from the premise that many parents of a child with a learning disability have expressed dissatisfaction with the type and amount of information they have received from professionals in relation to their child's difficulties, (Quine & Rutter, 1994). The questionnaire should, therefore, be relevant to this group of people.

### *Reliability*

This refers to how consistent the questionnaire is (Crookes & Davies, 1998). It was not possible to assess a number of different forms of reliability, for example test-retest reliability, as it was felt it would be unreasonable to ask parents to complete the questionnaire more than once. However inter-rater reliability i.e. the extent to which two or more raters agree (Crookes & Davies, 1998), was

assessed by having two independent raters score ten questionnaires based on the scoring system described above.

*A Short Form of the Questionnaire on Resources and Stress (QRS-F)*

*(Friedrich, Greenberg & Crnic, 1983)*

The QRS-F developed by Friedrich, Greenberg and Crnic, (1983), is a short form of the much longer Questionnaire on Resources and Stress (QRS) by Holroyd (1974). It comprises 52 items which are answered true or false. Friedrich et al. (1983) analysed the original QRS and found that 52 items appeared to be the most reliable. These were then factor analysed and four distinct factors were found which determined the four subscales of Parent and Family Problems, Pessimism, Child Characteristics and Physical Incapacitation. Examples of items from each subscale are given below:

Parent and Family Problems	Other family members do without things because of .....
Pessimism	I wonder what will happen to ..... when I can no longer take care of him/her
Child Characteristics	.....doesn't communicate with others of his/her age group
Physical Incapacitation	.....is able to go to the bathroom alone



Friedrich et al. (1983) found there to be a strong correlation between the total scores of the QRS and the QRS-F of .997. Scott, Sexton, Thomson and Wood (1989) examined the psychometric integrity of the QRS-F. They found that the QRS-F has good internal consistency, with a Cronbach's alpha of 0.92. They also found the subscales to have reasonable internal consistency, although the physical incapacity subscale had less consistency, possibly due to the small number of items in that subscale. Scott et al. (1989) concluded that the QRS-F was reasonably reliable and valid. The QRS-F is widely used in research with families with a child with a learning disability, (Frey et al., 1989, Dyson, 1993, Sanders & Morgan, 1997, Hoare et al., 1998, Hodapp et al., 1998).

*The Family Support Scale (Dunst, Jenkins and Trivette, 1984)*

This is a 20 item scale that lists 18 potential sources of support and space for two non-listed sources and asks parents to rate how helpful these supports are, including a not available rating if that source of support is not available to them. If help is available from a source it is rated on a five point scale from 'not helpful at all' to 'extremely helpful'. This allows both the number of supports available and the perceived helpfulness of available supports to be calculated. The supports listed include family and friends, support from the wider community such as parents groups and places of worship and also support from professional agencies including health and education.

Dunst, Trivette and Hamby (1994) measured the internal consistency of the scale and found that Cronbach's alpha was 0.79. They also found test-retest

reliability for the whole scale to be  $r = .91$ . Frey, Fewell and Vadasy (1989) reported good discriminant and content validity for the scale.

### **Power Analysis**

There has been little research examining the effect size of differences between parents of children with a specific versus non-specific learning disability diagnosis. Therefore the estimates will be based on research carried out in relation to differences between parents of children with different specific diagnoses. These have reported mainly medium to large effect sizes, e.g. Abbeduto et al. (2004) and Sanders and Morgan (1997). The current study aims to explore whether there are differences in the information and support parents receive and also parental stress between parents of a child with a specific diagnosis and parents of child with a non-specific diagnosis. These potentially are two groups of parents who are likely to have had quite different experiences regarding the information they have received, (Quine & Rutter, 1994) and therefore a large effect size is anticipated. A large effect size can be considered to be in the range 0.35-0.8, depending on the test used (Cohen, 1992).

The results will be analysed using a variety of statistical tests, of which the main one will be t-tests, for which Cohen (1992) recommends group sizes of 26 per group for a large effect size.

### **Statistical Analysis**

The data was analysed using SPSS 11 for Windows Student Version.

# Results

Demographic information relating to the current age of child, age of child at diagnosis, child’s diagnosis and the terminology that has been used to describe the child’s difficulties will be presented. This will be followed by information about the inter-rater reliability of the demographic, diagnosis and information questionnaire and the reliability of the QRS-F and Family Support Scale. Finally the results will be presented in relation to each of the hypotheses outlined in the introduction, along with analysis of parents’ qualitative comments.

## Demographic Information

### *Age of children*

Table 1 shows the mean, standard deviation, minimum and maximum age for the children with a specific and non-specific learning disability diagnosis. An independent samples t-test was conducted between the two diagnostic groups with regard to current age. There was found to be no significant difference between the two groups on current age, ( $t(43) = -0.082$ ;  $p = 0.935$ ).

*Table 1. Current age of children*

Diagnosis	Mean current age	Standard Deviation	Minimum	Maximum
Specific	9.23	3.48	5	17
Non-specific	9.31	2.80	5	16

*Age of child at diagnosis*

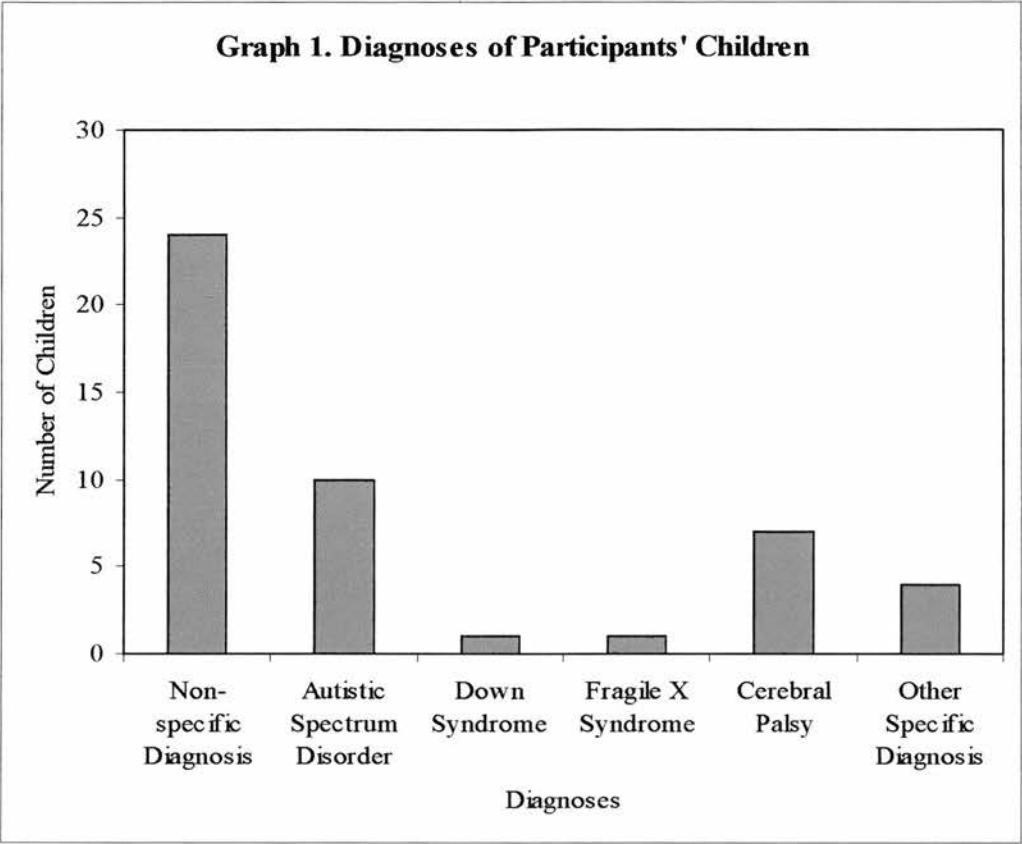
Table 2 illustrates the mean, standard deviation, minimum and maximum age at diagnosis for the children with a specific and non-specific learning disability diagnosis. An independent samples t-test was conducted between the two diagnostic groups with regard to age at diagnosis. There was found to be no significant difference between the two groups on age at diagnosis, ( $t(41) = 0.365$ ;  $p = 0.717$ ).

*Table 2. Age of child at diagnosis*

Diagnosis	Mean age at diagnosis	Standard Deviation	Minimum	Maximum
Specific	2.22	1.98	0	7
Non-specific	2.00	1.92	0	7

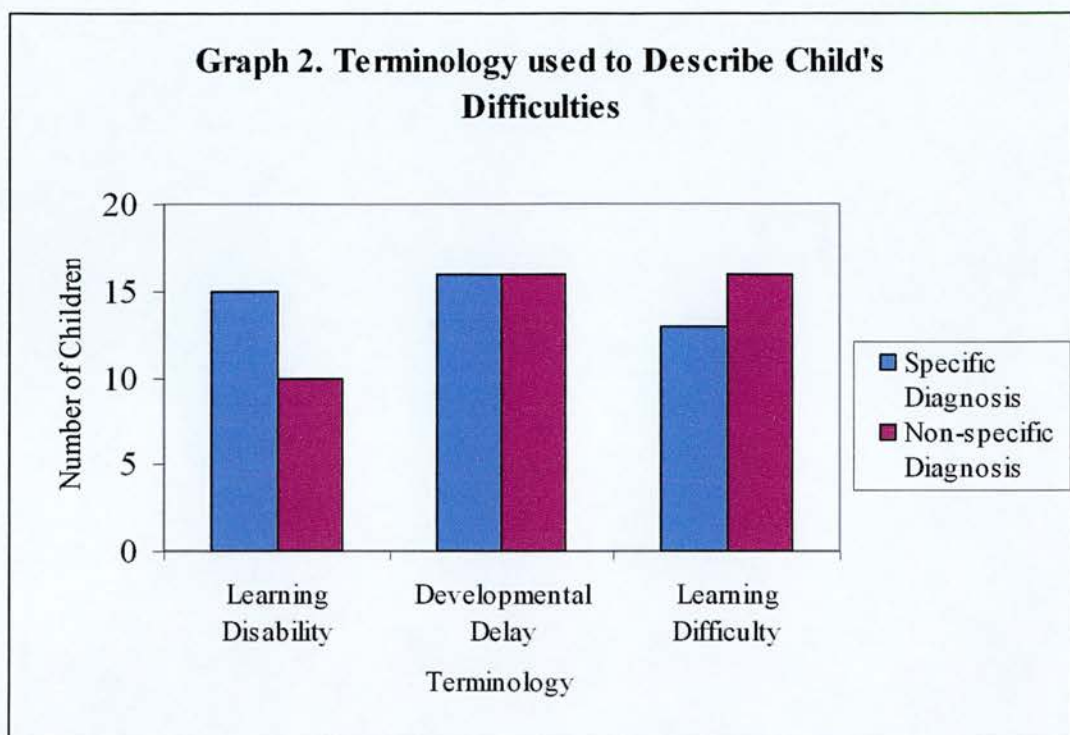
*Diagnoses*

The specific diagnosis group covered a range of different diagnoses with the most frequent being Autistic Spectrum Disorder and Cerebral Palsy. The group also included some rarer diagnoses which were grouped together as ‘other specific diagnosis’ and comprised Smith-Magenis syndrome, Angelman Syndrome, Autonomic Seizure Disorder and Trisomy 13. Graph 1. below displays the frequency of the different diagnoses.



*Terminology*

Children were often referred to using more than one of the different terms, hence the numbers displayed in graph 2 below add up to more than the number in each group. Chi-square tests were conducted in relation to the terminology used with those with a specific and non-specific learning disability diagnosis. There was found to be no significant difference between the two diagnostic groups in use of the term learning disability to refer to their child’s difficulties, ( $X^2 = 2.616$ ,  $df = 1$ ,  $p = 0.106$ ). There was found to be no significant difference between the two diagnostic groups in use of the term developmental delay to describe their child’s difficulties, ( $X^2 = 0.045$ ,  $df = 1$ ,  $p = 0.831$ ). There was also found to be no significant difference between the two diagnostic groups in the use of the term learning difficulty to describe their child’s difficulties, ( $X^2 = 0.512$ ,  $df = 1$ ,  $p = 0.474$ ).



### *Understanding of terminology*

Thirty eight parents completed the section asking what they understood the terminology used to describe their child's difficulty to mean on the demographic, diagnosis and information questionnaire. Of these, 27 (73%) included a description that met the BPS (2000) definition of Learning Disability criteria of intellectual impairment. Two parents (5%) included a description that would meet the adaptive functioning impairment criteria of the BPS (2000) definition of Learning Disability. Four parents' (11%) description included both the intellectual impairment and impairment of adaptive functioning criteria of the BPS (2000) definition of Learning Disability. Table 3 illustrates examples of responses given by parents which meet the BPS (2000) criteria for a learning disability.

Table 3. Parents understanding of terminology used to describe their child’s difficulties

BPS (2000) criteria for a Learning Disability	Intellectual impairment	Adaptive functioning
Parents responses that were judged to meet the criteria	<p>‘her learning ability is impaired’</p> <p>‘he will be slow to learn things, if at all’</p> <p>‘she has problems with learning and understanding’</p>	<p>‘she has problems with everyday things like dressing and personal hygiene’</p> <p>‘She finds it harder to pick up and learn things like dressing herself and it takes her longer to understand and do everyday tasks’</p>

**Inter-rater reliability of the demographic, diagnosis and information questionnaire**

The tick box questions were analysed using Kappa as a measure of agreement and the questions that produced numerical scores were analysed using a Pearson’s correlation.

For all of the tick box diagnosis questions except one there was found to be complete agreement between raters, with a Kappa value of 1.000 and significance at the  $p = 0.005$  level. There was slight disagreement of the first diagnosis question of whether or not a child has a specific diagnosis, however this was only for one of the questionnaires scored and there was still a high level of agreement with a Kappa value of 0.800 and significance at the  $p = 0.01$  level. A Kappa value of above 0.75 is considered excellent (Clark-Carter, 1997). The correlations between the numerical answers for the information questionnaires revealed complete agreement on all items with  $r = 1.000$ . Further details of the analysis can be found in Appendix IV.

### **Reliability of the QRS-F and the Family Support Scale**

Reliability analysis of the QRS-F with the current sample produced a Cronbach's alpha of 0.7995, (0.7 is usually taken as the minimum value for a reliable test). Reliability analysis of the Family Support Scale with the current sample produced a Cronbach's alpha of 0.6755.

### **Results relating to hypotheses**

Prior to analysis the data was examined for departure from normality. None of the variables used in the analysis relating to the hypotheses were found to have significantly skewed distributions. The data from some of the questionnaires involved Likert scales and thus are not strictly interval data; however the scores used in the analysis were either sums or means of Likert scores and thus took on the characteristics of interval data. Coolican (2004) argues that t-tests are robust



enough to withstand some violation of the criteria for their use. When assumptions of parametric tests have been violated Fife-Shaw (2000) advocates analysing data with both parametric and non-parametric tests and if these produce results that are similar and non-contradictory then the parametric tests results can be reported as accurate. Non-parametric tests were conducted alongside the parametric analysis and found to produce the same results. Therefore the results from the parametric analysis are reported here.

### **Hypothesis one**

**Parents whose child has a diagnosis of ‘learning disability’ alone will have received less information about their child’s difficulties than parents whose child has a more specific diagnosis.**

Three variables were analysed in relation to the amount of information parents had received: number of sources from which parents had accessed information, the mean amount of information received from the different sources and the mean satisfaction rating for the information received. It was thought important to include the satisfaction with information received to allow for the possibility that parents may have received lots of information but be dissatisfied with the information, with quality of information possibly being more important than quantity.

*Number of sources from which parents had accessed information*

Table 4 illustrates the mean and standard deviation for the number of sources of information accessed by parents of a child with a specific and non specific learning disability diagnosis. An independent samples t-test showed that there was a significant difference between the numbers of sources from which parents had accessed information. Parents of children with a specific diagnosis accessed information from a larger number of sources than parents of children with a non-specific diagnosis, ( $t(45) = 2.445$ ;  $p < 0.01$ ).

*Table 4. Number of Sources of Information*

Diagnosis	Mean	Standard Deviation
Specific	6.22	1.48
Non-specific	5.08	1.69

*Amount of information received from sources*

Table 5 illustrates the mean and standard deviation for the amount of information parents of children with a specific and non-specific learning disability diagnosis had received. An independent samples t-test showed that there was no significant difference between the two groups with regard to the amount of information parents had received, ( $t(45) = 1.022$ ;  $p = 0.156$ ).

*Table 5. Amount of information received*

Diagnosis	Mean	Standard Deviation
Specific	18.17	8.02
Non-specific	15.88	7.41

*Mean satisfaction rating for information received*

Table 6 displays the mean and standard deviation for the mean satisfaction rating of parents with a child with a specific and non-specific learning disability diagnosis. An independent samples t-test showed that there was no significant difference between the mean satisfaction rating for information received between the two groups, ( $t(44) = -0.790$ ;  $p = 0.217$ ).

*Table 6. satisfaction with information received*

Diagnosis	Mean	Standard Deviation
Specific	2.96	0.80
Non-specific	3.19	1.10

Whilst there was only a significant difference on one of the measures of information received by parents, due to the small sample size it cannot be concluded that the null hypothesis is therefore true.

**Hypothesis two**

**Parents of children with a non-specific ‘learning disability’ diagnosis will have less access to support organisations than parents of children with a more specific diagnosis.**

Three variables were considered in relation to hypothesis two: the number of parents who had accessed information from support organisations, the amount of information received from support organisations, satisfaction with information from support organisations.

*Parents accessing information from support organisations*

Table 7 displays the number of parents from each diagnostic group that had accessed information from a support organisation. A chi-square was conducted with regard to whether there was a significant difference between the numbers of parents with a child with a specific and non-specific learning disability diagnosis who had accessed information from a support organisation. There was found to be a significant difference, with more parents of children with a specific diagnosis having accessed information from support organisations than parents of children with a non-specific diagnosis, ( $X^2 = 3.577$ ,  $df = 1$ ,  $p < 0.05$ ).

*Table 7. Parents accessing support organisations*

Diagnosis	Number of Parents
Specific	14
Non-specific	8

### *Amount of information from support organisations*

Table 8 displays the mean and standard deviation for the amount of information received from support organisations by parents of children with a specific and non-specific learning disability. An independent samples t-test showed that there was no significant difference between the amount of information received from support organisations by parents of children with a specific and non-specific diagnosis, ( $t(21) = -0.116$ ;  $p = 0.455$ ).

*Table 8. Amount of information from support organisations*

Diagnosis	Mean	Standard Deviation
Specific	2.43	1.95
Non-specific	2.33	1.87

### *Satisfaction with information from support organisations*

Table 9 displays the mean and standard deviation for the satisfaction with information from support organisations for parents of children with a specific and non-specific learning disability diagnosis. An independent samples t-test revealed that there was no significant difference in satisfaction with information from support organisations between the two diagnostic groups, ( $t(20) = -.328$ ;  $p = 0.746$ ).

*Table 9. Satisfaction with information from support organisations*

Diagnosis	Mean	Standard Deviation
Specific	2.50	1.65
Non-specific	2.75	1.83

**Hypothesis Three**

**Parents of children with a specific learning disability diagnosis will have more access to professional support than parents of children with a non-specific learning disability diagnosis.**

Both the number of professional services available and the perceived helpfulness of these services were considered in relation to hypothesis three.

*Total number of professional services available as support*

Table 10 displays the mean and standard deviation for the total number of professional services available to parents of children with a specific and non-specific learning disability diagnosis. An independent samples t-test showed that there was no difference in the number of professional services available to parents of children with a specific or non-specific learning disability diagnosis ( $t(45) = 0.551; p = 0.585$ ).

*Table 10. Number of professional services available as support*

Diagnosis	Mean	Standard Deviation
Specific	3.48	1.38
Non-specific	3.29	0.91

*Level of helpfulness of professional services*

Table 11 displays the mean and standard deviation for the level of helpfulness of professional services as rated by parents of children with a specific and non-specific learning disability diagnosis. An independent samples t-test showed that there was no significant difference in level of helpfulness of professional services between parents of children with a specific and non-specific diagnosis, ( $t(45) = 0.394$ ;  $p = 0.696$ ).

*Table 11. Level of helpfulness of professional services*

Diagnosis	Mean	Standard Deviation
Specific	2.40	1.18
Non-specific	2.26	1.10

**Hypothesis Four**

**Parents of children with a non specific ‘learning disability’ diagnosis will experience greater levels of stress than parents of children with a more specific diagnosis.**

Three variables were considered in relation to hypothesis three, the QRS-F total perceived stress, the QRS-F parent and family problems score and the QRS-F pessimism score.

### *Total perceived stress*

Table 12 illustrates the mean and standard deviation for the QRS-F total perceived stress score of parents with a child with a specific and non-specific diagnosis. An independent samples t-test showed that there was no significant difference in total perceived stress between parents of children with a specific or non-specific learning disability diagnosis, ( $t(45) = 1.302$ ;  $p = 0.100$ ).

*Table 12. Total perceived stress*

Diagnosis	Mean	Standard Deviation
Specific	29.70	9.82
Non-specific	25.75	10.90

### *Parent and family problems*

Table 13 illustrates the mean and standard deviation for the QRS-F parent and family problems score for parents of children with a specific and non-specific learning disability diagnosis. An independent samples t-test showed that there was no significant difference in the QRS-F parent and family problems score between parents of children with a specific or non-specific diagnosis, ( $t(45) = 1.354$ ;  $p = 0.091$ ).

*Table 13. Parent and family problems*

Diagnosis	Mean	Standard Deviation
Specific	10.65	5.33
Non-specific	8.58	5.14



### *Pessimism*

Table 14 illustrates the mean and standard deviation for the QRS-F pessimism scores for parents of children with a specific and non-specific learning disability diagnosis. An independent samples t-test showed that there was no significant difference between the pessimism scores of parents of children with a specific or non-specific diagnosis, ( $t(45) = 0.276$ ;  $p = 0.392$ ).

*Table 14. Pessimism*

Diagnosis	Mean	Standard Deviation
Specific	7.65	2.66
Non-specific	7.46	2.15

None of the variables considered in relation to stress revealed a significant difference between parents or children with a specific or non-specific diagnosis, however it cannot be concluded that the null hypothesis is true due to the small sample size.

## **Hypothesis Five**

**Lower levels of information and support will be associated with greater levels of stress in parents of children with a learning disability.**

The relationships between information, support and stress variables were examined for the entire sample using Pearson's correlations.

### *Information and Support*

There was found to be a significant relationship between the number of sources from which parents had accessed information and their total number of supports, ( $r = 0.333, p < 0.05$ ). The total level of available support was associated with the number of sources of information accessed by parents ( $r = 0.344, p < 0.05$ ). There was also a significant relationship between the total level of available support and the amount of information received, ( $r = 0.545, p < 0.001$ ). In addition, a significant relationship was found between the total level of available support and the mean satisfaction with information received, ( $r = 0.453, p < 0.01$ ).

### *Stress*

None of the stress variables had a significant relationship with any of the information or support variables.

**Analysis of Further Comments**

In total, 37 parents completed the further comments section of the demographic, diagnosis and information questionnaire. Nineteen of these had a child with a specific learning disability diagnosis and 18 had a child with a non-specific diagnosis. The parents’ comments fell into six broad themes: the impact of having a non-specific diagnosis, the impact of a rare diagnosis, information provision, not being listened to, other parents and positive comments.

*Impact of a non-specific diagnosis*

Six of the parents from the non-specific diagnosis group commented on what having no specific diagnosis had meant for them. The comments were focussed on lack of knowledge of what the future held for their child and not knowing why their child has the difficulties. Table 15 gives examples of parents’ comments relating to having no specific diagnosis for their child.

*Table 15. Impact of a non-specific diagnosis*

Number of parents who commented	Percentage	Examples of comments
6 (from the non-specific diagnosis group)	25% (of non-specific diagnosis group)	‘As no official diagnosis, information about what future holds is very limited’ ‘Having no diagnosis makes it difficult to know what to expect from the child now and in the future’ ‘Endless tests but no diagnosis makes it hard to move on as don’t understand why she is like she is’

*Rare conditions*

Four of the parents from the specific diagnosis group reflected on the impact of the diagnosis of a rare condition. Their comments focussed on lack of information due to lack of knowledge amongst professionals and having to find information for themselves. Table 16 gives examples of parents’ comments relating to their child having a rare diagnosis.

*Table 16. Rare conditions*

Number of parents who commented	Percentage	Examples of comments
4 (from the specific diagnosis group)	17% (of the specific diagnosis group)	‘Condition very rare so hardly anyone is able to give information’ ‘Very little information about the syndrome. So disappointed in the information and advice about the syndrome I’m writing my own book’

*Information provision*

Twelve of the parents commented on the information they had received and the process of seeking information. Of these, four parents commented on the lack of and desire for more information. Four commented that a lot of the information provided was factual but there was little practical advice on how to manage/cope. Three parents commented on the need to ask for information and the variability of information provision from different sources and at different times. One parent commented that there can be information overload and having lots of professionals involved can lead to more stress.

Table 17 gives examples of parents' comments relating to their experiences of information provision.

*Table 17. Information provision*

Number of parents who commented	Percentage	Examples of comments
12	26% (of whole sample)	<p>'I just wish there was more information and support'</p> <p>'lots of literature but no real practical advice'</p> <p>'If you need information then you have to ask for it'</p> <p>'At one point there were ten professionals involved with our son; this actually resulted in more stress!'</p>

### *Not being listened to*

Three parents' comments reflected a feeling of not being listened to. These comments focussed on the parent knowing something was 'wrong' with their child but professionals not listening and being fobbed off for months or years before eventually receiving any information and support. Table 18 gives an example of a parent's comment relating to their experience of not being listened to.

*Table 18. Not being listened to*

Number of parents who commented	Percentage	Examples of comments
3	6% (of whole sample)	'Doctors finally listened to me at ten months, I knew something was wrong - up until then I was a "paranoid mother".'

### *Other parents*

Three parents reflected that other parents had been a very valuable source of information and support, at times more useful than professionals. Table 19 gives an example of parents' comments about the helpfulness of other parents.

*Table 19. Other parents*

Number of parents who commented	Percentage	Examples of comments
3	6% (of whole sample)	'Most information and support has come from other parents'

### *Positive comments*

Nine parents made positive comments about the information and support they had received. Five parents commented on how helpful school staff had been. Two parents commented that the professionals involved with their child were a valuable source of information and support. Three parents singled out individual professionals as being particularly helpful. Table 20 gives examples of positive comments made by parents.

Table 20. Positive comments

Number of parents who commented	Percentage	Examples of comments
9	19% (of whole sample)	'Professionals have been a great source of information and support' 'School have been a wonderful support'

## **Discussion**

The discussion will begin by restating the aims of the research followed by a summary and discussion of the results. The methodological limitations of the current study will then be discussed, followed by the clinical and ethical implications of the current findings and suggestions for further areas of research.

### **Section one: Discussion of results**

This section will begin by re-stating the aims of the current study, followed by a summary of and discussion of the results in relation to the main areas of interest and hypotheses.

#### *1.1 Aims of the current study*

The current study aimed to investigate whether the following varied according to whether a child receives a diagnosis of 'learning disability' or a more specific diagnosis:

- ❖ Amount of information parents receive about their child's difficulties
- ❖ Parental access to support
- ❖ Levels of parental stress

In relation to support, this study looked at the sources of support, in particular the use of support organisations and professional services. In addition, the study addressed whether the amount of information and support parents received was related to the amount of stress they experienced.



## *1.2 Summary and discussion of results*

This section will provide a summary and discussion of results in relation to demographic information, reliability of the measures used, the five original hypotheses and parents' further comments.

### *1.2.1 Demographic Information*

There was found to be no significant difference between the current age of the children with a specific learning disability diagnosis and the children with a non-specific learning disability diagnosis. There was also found to be no significant difference between the age at diagnosis of the children with a specific learning disability diagnosis and the children with a non-specific learning disability diagnosis.

This is in contrast to Quine and Rutter (1994) who found that children with a non-specific diagnosis were likely to have waited longer for diagnosis than children with a specific diagnosis. This suggests that in the current sample experience of the diagnostic process, whether it resulted in a specific or non-specific diagnosis, may have been similar for all participants in terms of length of wait before receiving a diagnosis. One possible reason for this is that two of the three areas participants were recruited from, have community assessment teams specifically for pre-school age children. In these areas any child that a health visitor feels has developmental difficulties is referred to the multidisciplinary team for assessment which often results in diagnosis, whether specific or non-specific. Thus in these areas, children that are struggling

developmentally receive a multidisciplinary assessment before the age of five, regardless of whether their difficulties are due to a specific diagnosis.

In relation to diagnosis the specific diagnosis group contained a variety of different diagnoses with the majority having diagnoses of Autistic Spectrum Disorder or Cerebral Palsy. Five participants' children had rarer diagnoses such as Fragile-X syndrome and Smith-Magenis Syndrome.

The terminology used to refer to the children's difficulties was similar whether they had a specific or non-specific diagnosis. More of the specific diagnosis group were referred to as having a learning disability and slightly more of the non-specific group were referred to as having a learning difficulty, however these differences were not found to be significant. Furthermore many of the participants' children had more than one term used to describe their difficulties. As mentioned in the introduction different terminology is used by different professionals, with health and social care mainly using the term learning disability, as do official government documents in these fields e.g. 'The same as you?' (Scottish Executive, 2000). However, professionals in education services almost never refer to learning disability; the Education (Additional Support for Learning) (Scotland) Act 2004 simply refers to additional support needs. Thus the fact that many of the children were referred to using more than one term is perhaps not surprising as they are likely to have had contact with both health and education professionals. With regard to age at diagnosis and terminology used to describe the child's difficulties the two groups of parents appear to have had similar experiences. These similarities may be due to the participants being served by the same health and education services regardless of their diagnosis.

Thus the professionals in these services may use the same terminology to refer to learning disability regardless of the cause.

Parents' understanding of the terminology used to describe their child's difficulties was relatively good; with the majority (73%) describing difficulties that would meet one of the BPS (2000) criteria for learning disability of intellectual impairment. This is perhaps surprising given the use of different terminology, often with a child's difficulties being referred to with more than one term. Furthermore professionals and the public have been shown to have at times a limited understanding of learning disability, (Antonak et al., 1989, McKenzie et al., 1999a).

### *1.22Reliability*

There was found to be good inter-rater reliability of the Demographic, Diagnosis and Information Questionnaire. The reliability of the QRS-F with the current sample was also found to be good. However, the reliability of the Family Support Scale with the current sample fell just below the value that is usually accepted as a minimum for a reliable scale. The data from the Family Support Scale was only used in the analysis relating to two of the hypotheses concerning professional support and the relationship between information, support and stress.

### *1.23 Results relating to hypotheses*

The results of the analysis relating to each hypothesis will be summarised and discussed with regard to possible explanations for the current findings and comparison to the research literature.

#### *1.231 Hypothesis one*

**Parents whose child has a diagnosis of ‘learning disability’ alone will have received less information about their child’s difficulties than parents whose child has a more specific diagnosis.**

There is considerable confusion around the term learning disability; with even professionals working in the field having limited knowledge of what the term actually encompasses (McKenzie et al., 1999a). Education services do not use the term learning disability at all. Furthermore, parents of a child with a broad learning disability diagnosis are more likely to have to wait longer for diagnosis which is associated with higher dissatisfaction with the diagnostic process (Quine & Rutter, 1994). Thus it would seem likely that parents whose child has a non-specific learning disability diagnosis will have received less information about their child’s difficulties than those whose child has a more specific diagnosis.

There was found to be a significant difference in the number of sources parents accessed information from. Parents of children with a specific diagnosis accessed information from a significantly larger number of sources than parents

of children with a non-specific diagnosis. However there was found to be no significant difference between parents of children with a specific diagnosis and parents of children with a non-specific diagnosis with regard to the amount of information they had received or their mean satisfaction rating with the information received.

The difference in the number of sources of information accessed by the two groups maybe explained by the findings described below that more of the specific diagnosis group had accessed information from support organisations. Furthermore greater numbers accessing support organisations might also lead to accessing information from these organisations' websites which would count as a further source of information. A factor in the groups' similarity regarding amount of information may in part be due to 22% of the specific diagnosis group having rare specific diagnoses which some parents commented led to less available information due to lack of knowledge amongst professionals. This is discussed further when considering parents' comments on the impact of a rare diagnosis.

Research on support provision to families with a child with a learning disability has found that it is the quality and nature of support, rather than number of supports that positively impacts on families, (Frey et al., 1989, Hassall et al., 2005). This may also be true for the information which parents receive, which may account for similar levels of satisfaction despite different numbers of sources of information.

Quine and Rutter (1994) found length of wait for diagnosis to be related to satisfaction with information provided by professionals; with a longer wait associated with higher dissatisfaction. As there was found to be no difference in the age of the child at diagnosis, this may be the reason that satisfaction with the information they have received from professionals was similar for the two groups of parents. This contrasts with the findings of Quine and Rutter (1994) who reported that those with a non-specific learning disability diagnosis waited longer for diagnosis and were more dissatisfied with the information they'd received.

Whilst there was a difference in number of sources of information accessed by the two groups, there was no significant difference in the amount of or satisfaction with the information provided. Somewhat similar findings were found in relation to access to support organisations, discussed below.

### *1.232 Hypothesis two*

**Parents of children with a non-specific 'learning disability' diagnosis will have less access to support organisations than parents of children with a more specific diagnosis.**

There are many different disability organisations which provide information which is diagnosis specific e.g. Scottish Society for Autism, Down Syndrome Scotland. Diagnosis specific organisations are able to provide parents with information on the development and likely difficulties their child may have due to their specific diagnosis. However, due to the broad spectrum of difficulties

and abilities covered by the term learning disability, it was hypothesised that organisations for those with a learning disability may be less able to provide information about the likely development and difficulties of an individual with a learning disability diagnosis.

This study found that significantly more parents of children with a specific diagnosis had accessed information from support organisations than parents of children with a non-specific diagnosis. However there was no significant difference in the amount of or satisfaction with information received from support organisations between the parents of children with a specific diagnosis and the parents of children with a non-specific diagnosis

There are several possible reasons that fewer parents with a child with a non-specific diagnosis accessed support organisations. More than half of the non-specific diagnosis group were not referred to as having a learning disability at all. Thus, if the term learning disability has not been used, parents are unlikely to see learning disability organisations as applicable and relevant to their child. Furthermore education professionals do not use term learning disability, as evidenced by the Education (Additional Support for Learning) (Scotland) Act 2004 which has no mention of the term learning disability yet includes those with a learning disability as being covered by the Act. Education professionals may, therefore, be less likely to know about learning disability organisations or their relevance and as a result may be less likely to recommend such organisations to families. However, if a child has a more specific diagnosis

such as Autistic Spectrum Disorder, education professionals would have little difficulty in seeing the relevance of the Scottish Society for Autism.

There was no difference in the amount of and satisfaction with information from support organisations between the two groups. This suggests that if those with a non-specific diagnosis are able to access an appropriate support organisation they are likely to get similar quality information as those accessing specific diagnosis organisations. Therefore access to, rather than what the organisations provide seems to be the key difference. It is important to note that accessing support organisations does not necessarily result in gaining more information about their child's difficulties. This is highlighted by the fact that whilst more of the specific diagnosis group had accessed support organisations overall there was no significant difference in the amount of information parents reported they had received about their child's difficulties.

It is of interest that relatively low numbers of the current sample, (47%) had accessed a support organisation, despite relatively low satisfaction with the support provided by professional services. This raises the question of the availability of support organisations to families in Scotland. One of the possible reasons that low numbers had accessed support organisations is professionals may not know which organisations would be appropriate to recommend to families. Coid and Crombie, (2001) found that in Scotland there was often a lack of knowledge in the NHS about the existence, activities and financial situation of voluntary organisations. They found this to have an adverse affect on planning of healthcare and advocate developing databases of voluntary



sectors to facilitate communication and partnership between health and voluntary organisations. This was a detailed study of knowledge of voluntary organisations across the NHS in Scotland. Professionals can often be aware of their lack of knowledge of appropriate resources, Lennox, Diggins and Ugoni (1997) surveyed GPs regarding barriers to their providing adequate healthcare to people with a learning disability. Lennox et al. (1997) found that one of the barriers identified by GPs was an inadequate knowledge of the services and resources available.

In addition, some of the most well known learning disability support organisations such as Mencap do not have individual branches in Scotland which may affect access to support and information there. There are Scotland specific organisations such as Enable however it is not known how familiar these are to the general public and professionals. Likewise, internet searches for information about both learning disability generally or specific syndromes e.g. Down Syndrome, tend to result initially in a link to the English based headquarters. Thus those in Scotland may find it more difficult to access local support organisations. Having done so, however, the information provided by Scotland specific organisations is likely to be of a similar standard to UK organisations as there is often one umbrella organisation that devises the information.

Thus there was a clear difference in the number of parents who had accessed support organisations from each group, however there was no such difference in

amount of, or satisfaction with information from support organisations. The related issue of access to professional support is discussed below.

### *1.233Hypothesis Three*

**Parents of children with a specific learning disability diagnosis will have more access to professional support than parents of children with a non-specific learning disability diagnosis.**

Professionals have been found to have at times quite a limited understanding of what the term learning disability actually means (McKenzie et al., 1999a). McKenzie, Paxton, Murray, Matheson and McCaskie (1999) found that 21% of health professionals and 83% of social care staff held a misconception about the term learning disability. Such misconceptions included the view that learning disability was a physical disability and confusing learning disability with learning difficulties such as dyslexia. This is despite a legal obligation for those caring for people with a learning disability to know what that person's specific difficulties and needs are. This is exemplified in the concept of duty of care which acknowledges that the term learning disability includes a potential to expose oneself to risk of harm (Nunkoosing, 1995). A duty of care exists for professionals working with people with learning disability to protect the welfare of that individual (McKay, 1991). This obviously requires a full understanding of their difficulties and needs. Thus if a child's only diagnosis is learning disability, professionals may have less understanding of their support needs than a child who has a more specific diagnosis which they may be more knowledgeable about.

In the current sample there was found to be no significant difference in either the number of professionals involved or the perceived level of helpfulness of professionals between parents of children with a specific and non-specific learning disability diagnosis.

The number of professional supports available to families was relatively high, with the mean being three out of a possible four listed professional supports. However the mean satisfaction for the overall sample was quite low and fell in the level of helpfulness described as ‘sometimes helpful’. This suggests that whilst professionals are available to parents they might not always be meeting their needs. This is backed up by Donovan (1988) who found that whilst mothers did rely on professionals for support they found some of the interventions offered to them unhelpful and used such interventions infrequently. Thus it is perhaps the satisfaction with professionals that is the important issue. Hassall et al. (2005) found that it was the quality and nature of support that was more important to families rather than the number of supports. So whilst the current sample have relatively high numbers of professionals available for support, it is perhaps the nature of that support that has led to relatively low satisfaction levels. The low satisfaction with professional support may play a role in the stress levels of parents, however the two groups did not differ in their satisfaction level; whether the two groups differ with regard to stress is discussed in the following subsection.

#### *1.234 Hypothesis Four*

**Parents of children with a non-specific 'learning disability' diagnosis will experience greater levels of stress than parents of children with a more specific diagnosis.**

Parents with a child with a learning disability have been found to experience greater levels of stress than those whose children do not have a learning disability (Dyson, 1993, 1997). Parents of children with a non-specific learning disability diagnosis are more likely to have to wait, at times for years, before their child receives a diagnosis and information is provided compared to parents of children with a more specific diagnosis (Quine & Rutter, 1994). Support has been found to play an important part in reducing parental stress in families with a child with a learning disability (Hassall et al., 2005, Hodapp et al., 1998). Thus if parents of a child with a non-specific learning disability diagnosis receive less information and support than parents whose child has a more specific diagnosis it is possible that they will experience higher levels of parental stress.

Furthermore there are many factors that have been found to impact on parental stress in families with a child with a learning disability. Such factors include the levels of behavioural difficulties and specific diagnosis of the child (Abbeduto et al., 2004, Beck et al., 2004, Sanders & Morgan, 1997). The finding that different specific diagnoses can be associated with differing stress levels suggests that perhaps also different diagnoses with regard to specificity may be associated with differing stress levels.

There was, however, found to be no significant difference in the current study, between parents of children with a specific diagnosis and parents of children with a non-specific diagnosis with regard to:

- Total perceived stress score on the QRS-F
- Parents and family problems score on the QRS-F
- Pessimism score on the QRS-F

There are several possible reasons for the lack of difference in stress levels between the two groups. It could be due to the lack of difference in information and support received by the two groups of parents. Leino-Kilpi, Ilre, Suominen, Vuorenheimo and Valimaki (1993) in a review of the information provided to people coping with health problems, found evidence that the provision of information helped patients cope with health difficulties and stress. This study, however, referred to physical health and the findings may not necessarily be replicated in a learning disability population. However it must be remembered that there is an absence of research in relation to information provision using a child learning disability population. There is considerable research suggesting that support impacts on stress e.g. Hassall et al. (2005). Thus if information and support are similar for the two groups this might lead to similar levels of stress.

There is also the consideration of the many factors that can impact on stress in families with a child with a learning disability as outlined in the introduction. The child's level of communication skills and behaviour problems have been found to impact on parental stress in families with a child with a learning

disability (Beck et al., 2004, Frey et al., 1989, Kwai-Sang Yau & Li-Tsang, 1999). Parental factors such as coping style, parenting self-esteem and locus of control have also found to impact on stress levels (Essex et al., 1999, Hassall et al., 2005). Furthermore different specific diagnoses have been found to be associated with different levels of parental stress (Abbeduto et al., 2004, Sanders & Morgan, 1997). None of the above factors were controlled for in the current study and thus the potential impact of behaviour problems, parental coping style and different specific diagnoses may have served to counteract any difference in stress due to having a specific or non-specific learning disability diagnosis. In particular 43% of the specific diagnosis group of the current sample had an Autistic Spectrum Disorder diagnosis. This diagnosis has been found to be associated with higher parental stress levels, (Abbeduto et al., 2004, Sanders & Morgan 1997). Thus any potential reduction in stress due to having a specific diagnosis may have been counteracted by what that specific diagnosis was for a large proportion of that group.

The lack of difference between the two groups with regard to information, support and stress raises the question of whether there is a relationship between these factors, this is discussed in the next subsection.

### *1.235 Hypothesis Five*

**Greater levels of information and support will be associated with lower levels of stress in parents of children with a learning disability.**

Leino-Kilpi et al., (1993) in a review of the information provided to people coping with health problems, found several studies produced evidence that the provision of information helped patients cope with health difficulties and stress. In families with a child with a learning disability Quine and Rutter (1994) found that parents frequently wanted more information than they had been provided with and found it difficult to gain information from professionals. Speedwell, Stanton and Nischal (2003) found that in families with a child with a visual impairment the majority of parents thought they should have been given information by professionals earlier than they had, regarding their child's difficulties. Speedwell et al. (2003) suggest that parents' wishing they had received information earlier is suggestive of dissatisfaction with the amount and timing of information. Speedwell et al. (2003) were concerned with the visually impaired population and thus their findings are not necessarily directly transferable to the learning disability population.

However, there has been little research on the impact of information on parental stress in families with a child with a learning disability. The existing research coupled with clinical experience of parents saying that having to struggle to get information about their child's difficulties was stressful led to the hypothesis that information provision could play a role in parental stress.



There has been considerable research finding that support does impact on parental stress with higher levels of support being associated with less stress (Hassall et al., 2005, Hastings et al., 2002).

The present study found significant relationships between:

- The number of sources from which parents had accessed information from and their total number of supports
- The total level of available support and the number of sources which parents had accessed information from
- The total level of available support and the amount of information received
- The total level of available support and the mean satisfaction with information received

However there was found to be no significant relationship between the stress variables and any of the information and support variables.

Van Riper (1999) studied maternal perceptions of family-provider relationships and well-being in families with a child with Down syndrome. She found that mothers who felt their relationships with providers were positive were more satisfied with the service they received from these providers and also that they were more likely to seek help from health-care providers. This suggests that if families are satisfied with the service they receive they are more likely to seek



support from services. It may be that the same process could apply to the current sample where it was found that satisfaction with information received was associated with available support. One potential explanation for this relationship is that, parents were satisfied with their support, this led them to seek out more support and that was why they reported more available support.

No significant relationship between the stress variables and any of the information or support variables was found, despite research from other areas which suggests that this relationship is an important one. For example, van Riper (1991) found that satisfaction with services received was associated with higher levels of individual and family well-being for parents of children with Down syndrome. However this is a specific subsection of the learning disability population and thus the findings of van Riper (1991) do not necessarily apply to the learning disability population as a whole. Furthermore, Leino-Kilpi et al. (1993), in a review involving those with physical health problems, found evidence that information can help patients cope with stress. There has also been considerable research in relation to the link between support and parental stress, with higher levels of support being associated with reduced parental stress (Frey et al., 1989, Hassall et al., 2005, Hastings, Thomas et al., 2002). The results of the current study are at odds with these research findings. One explanation for this difference may be, as was noted previously, that there are many mediating factors involved in parental stress in families with a child with a learning disability (Beck et al., 1989, Essex, et al., 1999, Frey et al., 1989, Hassall et al., 2005). It may be that factors such as behavioural difficulties which, were found by Beck et al. (2004) to significantly predict maternal stress,

may have a greater impact on parental stress than information or support. Thus if a child has particularly difficult behaviour this may have such a detrimental effect on parental stress that provision of information and support does not appear to have any impact on stress levels.

The results relating to the hypotheses are based on analysis of data from fixed choice questions on questionnaires. What follows is a consideration of parents' comments in relation to their experiences of information, support and stress.

#### *1.24 Parental comments*

Thirty seven parents completed the further comments section of the demographic, diagnosis and information questionnaire. The parents' comments fell into six broad themes: the impact of having a non-specific diagnosis, the impact of a rare diagnosis, their experiences relating to information provision, experiences of not being listened to by professionals, other parents as a support and positive comments about the information and support they had received. These themes are similar to those reported by Carmichael et al. (1999), who looked at parents' experiences of their child receiving a diagnosis of Fragile-X syndrome. Carmichael et al. (1999) found that parents had had some positive experiences during diagnosis and made positive comments about individual professionals but they also found examples of parents not being listened to and the difficulties of a rare diagnosis.

### *1.241 The impact of a non-specific diagnosis*

It is the parents' comments about the impact of a non-specific diagnosis which lend weight to the generation of the original hypothesis that parents of children with a non-specific diagnosis will have received less information. Parents from this group commented specifically that lack of a specific diagnosis led to them feeling that they had no explanation for their child's difficulties and likely future development. These comments suggest that parents of children with a non-specific diagnosis can feel that they have less knowledge and understanding of their child's difficulties due to a lack of specific diagnosis. None of the parents in the specific diagnosis group commented that they felt they had no explanation of their child's difficulties and likely development.

There was however found to be no difference between the information received in terms of amount and satisfaction by parents of children with a non-specific and specific learning disability diagnosis. A possible reason for this is the variety of different specific diagnoses covered by the specific diagnosis group. Whilst professionals have been found to be knowledgeable about specific diagnoses such as Down syndrome and Autistic Spectrum Disorder they have been found to have far less knowledge regarding rarer diagnoses such as Fragile X syndrome (York et al., 1999). In the current sample 52% of the specific diagnosis group had a diagnosis other than Down syndrome or Autistic Spectrum Disorder, as a result professionals may have been less knowledgeable and less able to provide information about these diagnoses. As noted by Carmichael et al. (1999) in their study involving parents of children with Fragile

X syndrome, the professional providing the diagnosis may have little knowledge of the condition and as a result provide little information and support to parents.

#### *1.242 The impact of a rare diagnosis*

There are also differences in the nature of the specific diagnosis that may account for the lack of information received by the specific diagnosis group. Five of the specific diagnosis group had rarer diagnoses such as Fragile-X and Smith-Magenis syndrome. The comments of parents of children with rarer diagnoses reflected that having a specific diagnosis does not always lead to more information. When a specific diagnosis is that of a rare condition, parents commented that, due to the rarity, professionals had little knowledge to impart to families regarding the condition. Carmichael et al. (1999) also found that some parents had experienced a lack of knowledge amongst professionals regarding the condition and as a result little information and support had been provided. A particularly notable comment reflected that the information provision had been so poor the parent was writing his/her own book on the subject.

#### *1.243 Information provision*

Parents' comments on information provision reflected varied experiences from the very positive to the very negative. This suggests that information provision to parents of children with a learning disability is not a uniform experience and this has implications for the services providing the information. The variability

of information provided to parents with the same condition is not a new finding. Scriven and Tucker (1997) investigated the written information provided to women patients with the same condition across 100 hospitals in England. They found that the quality, amount of information and the source of information varied dramatically between hospitals and ranged from well-produced, comprehensive information from a knowledgeable source to very poor quality information. Whilst Scriven and Tucker (1997) were concerned with information relating to physical conditions there is also some suggestion of variability in service provision from the learning disability research literature. McKenzie, Paxton, Murray and Matheson (2000) found that the composition of learning disability teams across Scotland varied with regard to professions making up the team. This has implications for families seen by the team, for example if a team did not have a speech and language therapist those with difficulties such as Autistic Spectrum Disorder, where communication is a key component, may not have access to the same assessment and information provision as those seen by teams with a speech and language therapist.

The current sample involved families seen by a number of different learning disability teams and services which may in part explain the variability in information provided. Parents' experiences of seeking help and information were also found to be variable and the experience of not being listened to by professionals is discussed below.

#### *1.244 Not being listened to*

Parents' comments regarding not being listened to are an area of concern for services. Whilst only three parents commented that they hadn't been listened to, this should still be regarded as three too many. The implications of the results for services will be discussed further in section two. Comments included parents knowing there was something wrong with their child but professionals not listening and treating them like 'a paranoid mother'. Similar experiences were found by Carmichael et al. (1999) with parents commenting that they had been told they were over-anxious or neurotic and had their anxieties ignored by professionals.

#### *1.245 Other parents*

As evidenced by one of the participants of the current sample commenting that information provision had been so poor she was writing her own book, parents can often become important sources of information and support for other parents. Participants did comment on the value of other parents as sources of information and support. The experiences of others in similar circumstances can often be a valuable source of knowledge, Scriven and Tucker (1997) noted that the best written information provided to patients about their condition is developed in consultation with previous patients with that condition as they are most likely to know what information is needed. However, professionals can play a valuable role as discussed in the subsection that follows.

### *1.246 Positive comments*

The positive comments of parents were largely praising particular services and this does give some hope for services, suggesting that professionals can and are providing valuable information and support to families. Carmichael et al. (1999) also found that some parents had positive experiences and had been provided with excellent support and information by professionals.

## **Section two: Clinical and ethical implications of the current research**

The results of the current study suggest that parents of children with a learning disability are not always getting the information and support they need. This section will begin by looking at the implications of the findings regarding information provision to families, followed by the use of terminology and support from professionals.

### *2.1 The diagnostic process and provision of information*

The age at diagnosis of the current sample was not found to differ between children with a specific or non-specific learning disability diagnosis. The mean age at diagnosis for the whole sample was two, which could be viewed as an acceptable wait for diagnosis in light of the knowledge that some disorders such as Autistic Spectrum Disorder are not necessarily apparent at earlier ages. However there should be some level of concern regarding the fact that some children waited until the age of seven before receiving a diagnosis. This has obvious implications for the families regarding potential lack of professional



support prior to diagnosis. Quine and Rutter (1994) found that parents whose child had a diagnosis that was not obvious at birth or only became apparent as the child developed often experienced a long period of anxiety and uncertainty before a firm diagnosis was made. This links to parents' experiences of not being listened to despite sensing something was wrong with their child, found both in the current research and that of Carmichael et al. (1999). Furthermore, with diagnosis comes recognition by others both professionals and the general public that there is a reason for a child's difficulties other than inadequate parenting. Several parents in the Carmichael et al. (1999) study commented that prior to receiving a diagnosis they were made to feel by professionals that their child's difficulties were in some way their fault. Thus length of wait for diagnosis and the provision of information and support, even when the diagnosis is yet to be confirmed, is an area services should be considering.

Similarly the experiences of parents whose children have a rarer diagnosis suggest professionals could be doing more to help these families. The excuse that because the diagnosis is rare the professional can offer little information or support should not be acceptable. Whilst there will always be gaps in professional knowledge, if one is in the position to make the diagnosis one should also be able to provide access to information and support either directly or by providing contact details of more specialist services and organisations. Both in the current study and in that of Carmichael et al. (1999) some parents had experiences of just being told what the diagnosis was and provided with no information at all on the condition. Carmichael et al. (1999) recommend that results of assessment and diagnosis should always be given by someone with



knowledge of the condition. There is also the consideration of the form of the information provided, a recent Cochrane review by Johnson, Sandford and Tyndall (2003) concluded that both verbal and written information should be provided when communicating about care issues with patients and significant others. Furthermore parents had a better understanding of their child's care needs on discharge from hospital when provided with written as well as verbal information. This was not investigated in the current study and part of the variability in satisfaction with information may be accounted for by differences in the format information was provided in.

Importantly two of the areas from which the current sample was drawn are covered by a health board that has little specialist provision for children with a learning disability. In this health board there is no specialist team for children with a learning disability, instead there is just a part-time clinical psychologist working with children with a learning disability. Nursing, paediatric and other services are provided through mainstream services that do not always have the knowledge or at times motivation to meet these families' needs. This may go some way to explain the lack of information and support families have received. The Quality Indicators for Learning Disabilities (NHS Quality Improvement Scotland, 2004) include the need for children with a learning disability "to have access to specialist multidisciplinary/multi-agency community services". However, it is clear that such needs as outlined by NHS policy are far from being met in some areas. McKenzie et al. (2000) found that professional composition of learning disability teams varied across Scotland. This has implications for the provision of services to families if some professions are

only available in some areas. The McKenzie et al. (2000) findings related to adult services, however as few of the areas have specialist child learning disability teams access to professionals is likely to be even more difficult and variable for the child learning disability population.

The importance of provision of timely and relevant information has been highlighted by several studies (Carmichael et al., 1999, Quine & Rutter, 1994, Speedwell et al., 2003,) and is an area that should be considered in the design and development of services for families with a child with a learning disability. Hand in hand with accurate and appropriate information provision is the use of correct terminology by professionals. The implications of the variability in terms used is discussed in the following subsection.

## *2.2 Terminology use*

The majority of the participants' children had more than one term used to describe their difficulties. Interestingly despite the current sample being drawn from special schools and as such representing the more severe range of learning disability the most frequently used term was developmental delay. As one parent commented the term 'developmental delay can be misleading as we later discovered it is not a delay- he will never reach certain milestones'. The frequency of the term developmental delay also raises the question of whether professionals perhaps use this term as they feel it is less stigmatising and anxiety provoking for parents. Correctly used developmental delay does refer to a delay in reaching developmental milestones but these milestones will be

reached. However as highlighted above the term can be very misleading when used to refer to a child who has a learning disability and is not delayed, rather will never reach certain targets.

The terms learning disability and learning difficulty were also frequently used and as mentioned above many children were referred to with more than one term and often three different terms had been used to describe the child's difficulties. It is obvious that this could lead to confusion and misunderstanding of a child's difficulties and needs. As highlighted by McKenzie et al. (1999a, 1999b) professionals understanding of the term learning disability can be limited and this may play a role in the terminology professionals use with families. There is also the fact that education professionals and services do not use the term learning disability as reflected by the Education (Additional Support for Learning) (Scotland) Act 2004 where there is no mention of learning disability at all. This Act is supposed to be a means of gaining the necessary additional support and those with a learning disability make up a large proportion of those with additional support needs. Thus if education services do not use the term learning disability they are likely to use other terms and as a result families with contact with both education and health services are likely to hear professionals using different terms to describe the same difficulties. There is a clear need for consistent use of terminology across professions and services in order to minimise confusion and misunderstanding of the child's difficulties and needs. Accurate use of terminology has implications for the availability and helpfulness of professional support which is discussed below.

### *2.3 Support from professionals*

The participants in the current sample did have professionals available to them as support. However their relatively low ratings of how helpful these professionals were suggest that whilst professionals are available to families they are not necessarily meeting their support needs. Thus services should seek to meet the specific needs of individual families through consultation on what the family actually wants from professionals. However as mentioned above services for children with a learning disability can be limited and thus professionals can not always offer the amount and type of support they would like due to caseload and funding pressures. Research such as the current study should highlight the need for services for children with a learning disability as outlined by the Quality Indicators for Learning Disabilities (NHS Quality Improvement Scotland, 2004). It must also be noted that parents made positive comments about the support they had received from professionals. The professionals to receive the most praise were those connected with schools and education. This may be due to such professionals being continuously involved with children and their families providing ongoing support. Health and social care professionals on the other hand are more likely to have fixed-term contact with families at times of particular difficulty. These differences in contact type may well impact on how easy it is to build relationships with families and how such professionals are viewed by families.

### **Section three: Methodological issues of the current study**

This section will begin by considering the methodological limitations of the current study incorporating issues regarding sample size, representativeness of the current sample, mediating factors in parental stress, questionnaire use and statistical limitations followed by its relative methodological strengths

#### *3.1 Methodological limitations*

##### *3.1.1 Sample size*

One limitation of the current research is the small sample size. As mentioned in the introduction, gaining participants for research involving families with a child with a learning disability is a frequent difficulty. The low response rate may be due to the very lack of information and support along with parental stress that this study aimed to investigate. However a suitably large population of those attending special schools in three council areas was identified and 273 potential participants were invited to take part. The current sample only fell short of that needed by five participants, with the current study having a response rate of 17% and a response rate of 19% being needed for statistical power.

There has been little research examining the effect size of difference between parents of children with a specific versus non-specific learning disability diagnosis. Therefore the estimates for effect size were based on research carried out in relation to differences between parents of children with different specific

diagnoses. These have reported mainly medium to large effect sizes, e.g. Abbeduto et al. (2004) and Sanders and Morgan (1997).

The main analysis of the data involved t-tests, for which Cohen (1992) recommends group sizes of 26 per group for a large effect size. In the current study the numbers in each group felt just short of this number with 23 in the specific diagnosis group and 24 in the non-specific diagnosis group.

### *3.12 Representativeness of sample*

A further potential criticism of the study is that the participants did not reflect a representative sample and therefore the results of the study can not be generalised to other areas. There are a number of plausible reasons why many of the 273 potential participants who were originally approached chose not to take part. Gattuso, Hinds, Tong and Scrivasta (2006) investigated reasons for refusing to participate in clinical research in a paediatric oncology population. They found reasons not to participate fell into nine categories of: research methods too involved or burdensome, worried about another issue, not interested in research topic, unsure, topic too sensitive, design issues, personal trait such as shyness, situational factor such as illness and see no benefit for self in participating. Whilst the Gattuso et al. (2006) study involved medical research, their findings are potentially applicable to the current study and as there was no further contact with those who did not participate one cannot be sure of the reasons.

Despite this, 47 responses were received from people from mixed socio-economic backgrounds and a wide geographical area. They reflected a range of different diagnoses and ages of children. The current sample were served by at least five different health teams and social work departments, and this may be more as addresses of participants were unavailable and the special schools involved have large catchment areas and also took children from outside their area. As a result, it is likely that the participants represented the wider population to some extent.

### *3.13 Mediating factors and parental stress*

As was highlighted previously, there are many factors that impact on parental stress in families with a learning disability, only some of which were controlled for in the current study (e.g. age of child). As this was a postal questionnaire study with a limited time-frame it was not possible to match the two groups on factors such as parental education level or extent of child's behavioural problems, both of which have been found to play a role in parental stress (Beck et al., 2004, Hodapp et al., 1998). Thus it is possible that there are other differences within the sample, not specific to diagnostic group, which may affect the stress they experience. Child specific factors, such as level of problem behaviour and communication impairment, which impact on parental stress in families with a learning disability (Beck et al., 2004, Frey et al., 1989), vary across and within diagnoses and as such may well play a role in the levels of stress experienced by participants in the current sample. Furthermore, parent factors such as parental beliefs, cognitions and coping styles have all been found



to impact on parental stress (Essex et al., 1999, Hassall et al., 2005) which again varies from individual to individual irrespective of specificity of diagnosis.

A further consideration is that the measures used in the current study looked at parents' perceptions of information, support and stress. Parents' beliefs and cognitions have been found to affect the stress they experience; with those who have a higher level of parenting efficacy and self-esteem reporting lower stress levels (Frey et al., 1989, Hassall et al., 2005). This may play a role in the finding that there was no difference in information, support or stress between the two groups. Despite the different mediating factors in stress, the current research was interested in the relationship between information, support and stress and found that these factors alone do not seem to predict stress.

### *3.14 Questionnaire*

Some of the information in the study was gathered from a questionnaire devised by the author. As a result there may be questions over its reliability and validity. The questionnaire development would have benefited from a pilot study being conducted, this would have ensured that the questionnaire was appropriate for the population it was designed for and provided valuable feedback on item relevance and comprehension (Clark-Carter, 1997). As a result item selection and content, along with the face validity would not have been solely based on professional opinions. Furthermore it may have allowed test-retest reliability of the questionnaire to be assessed. Unfortunately it was not possible to conduct a pilot study within the current study due to the limited number of participants. As a result it was not possible to gain valuable feedback



from participants particularly regarding comprehension of what the questionnaire was asking of them. Therefore one cannot be sure that the questionnaire used in the current study was measuring what it was designed to.

Further improvements to the questionnaire could have involved asking participants to list sources of information they had used and rate these rather than a prescribed list of sources. Questions with a fixed list of alternatives can constrain the way respondents can answer, although as Clark-Carter (1997) notes the inclusion of a possible response of 'other' does provide greater flexibility and this was utilised in the questionnaire. Nevertheless further information about the sources valued by families may have been provided by more open questions. In the current study having a prescribed list of sources may have led families to think that only sources of the type listed were of interest to the study and as a result may not have included sources of information that were different in nature to those listed but none the less important to families. Thus valuable information may have been lost to the study through the format of the questionnaire items.

Future development of the questionnaire should also consider the use of alternatives to likert scales which can be very subjective in what they measure. Coolican (2004) highlights that a participant's scores on a likert scale only have meaning in relation to the scores in the distribution obtained from the rest of the sample. This is particularly relevant for the current where the questionnaire was devised by the researcher without a pilot study and thus there are already questions over what exactly the questionnaire is measuring in relation to what it

was designed to measure. It also has implications for whether the results would be comparable to a different sample from the same population.

However, while it was not possible to examine many forms of reliability and validity because of the nature of the questionnaire and the type of information it was designed to gather, objectivity, content validity, face validity, social validity and inter-rater reliability were examined.

With regard to objectivity the questionnaire items were informed by relevant research and the views of clinical psychologists working in the specialty. As such the questionnaire items were not influenced by the personal opinions of the researcher. Content validity was met by ensuring that questionnaire items were informed by or directly related to the relevant research literature, along with the clinical judgements of professionals working in the learning disability specialty. Face validity was established by gaining the views of professionals working in the specialty regarding whether they felt the questions reflected the area of interest. With regard to social validity the current questionnaire was developed from the premise that many parents of a child with a learning disability have expressed dissatisfaction with the type and amount of information they have received from professionals in relation to their child's difficulties, (Quine & Rutter, 1994). The questionnaire should, therefore, be relevant to this group of people.

Inter-rater reliability was assessed using Kappa for the tick box diagnosis questions. For all of the items except one there was found to be complete

agreement between raters, with a Kappa value of 1.000 and significance at the  $p = 0.005$  level, with a Kappa value of 0.800 and significance at the  $p = 0.10$  level for the remaining item. A Kappa value of above 0.75 is considered excellent (Clark-Carter, 1997). The correlations between the numerical answers for the information questionnaires revealed complete agreement on all items with  $r = 1.000$ . The implications of using data from questionnaires containing Likert scales is discussed in the next subsection.

The methodological limitations of the questionnaire devised for the study have implications for the interpretation of the results. The questionnaire not having undergone a pilot study raises questions over whether it is measuring what it was designed to. The results from the questionnaire may be highly subjective and influenced by different participants differing interpretations of what they were being asked. The lack of standardisation of the questionnaire through a pilot study may limit how far the results from the questionnaire, in relation to hypotheses one and two, can be generalised to a wider population of parents with a child with a learning disability.

### *3.15 Statistical limitations*

The analysis of the data was conducted using parametric tests despite some of the data involving variables which were not strictly interval data. However, Coolican (2004) argues that t-tests are robust enough to withstand some violation of the criteria for their use. Furthermore the analysis was initially conducted using both parametric and non-parametric tests and when these were

found to produce similar results and be non-contradictory the parametric analysis was judged to be accurate and reported in the results section, as advocated by Fife-Shaw (2000).

### *3.2 Methodological strengths*

Despite the limitations there are particular strengths of the current study. The method of recruitment aimed to make the sample as representative as possible with regard to range of diagnoses, both specific and non-specific along with socio-economic background of the families.

The current sample was recruited through special schools. This was an attempt to gain a wider cross section of families and not just those who are able to access information and support. Research sometimes recruits families through organisations such as parent groups or convenience samples of those in contact with researchers, (Beck et al., 2004, Carmichael et al., 1999, Hodapp et al., 1998) and by doing this are perhaps excluding those less able to access such supports.

The very nature of special schools within Scotland means that they often cover a relatively large geographical area, as compared to mainstream schools. As a result pupils attending a special school often come from a variety of backgrounds with regard to parental education and occupational status. Furthermore the three council areas included in the current study have catchment areas that are very diverse from relatively rural to very urban

settings. Thus it is hoped that whilst the groups were not matched on social factors, participants were recruited from a range of different social backgrounds.

The issue of having a non-specific learning disability diagnosis compared to a more specific diagnosis appears to have been little studied. However children with a non-specific diagnosis make up a significant proportion of the learning disability population, just over 50% of the current sample, and as such their need for greater clarity and quality of information should not be ignored. This study is an initial exploratory study that should be built upon by further research. Possible areas for future research are discussed in the next section.

#### **Section four: Further research**

This section will look at implications for further research based on the findings of the current study. It will begin by looking at the provision of information, followed by terminology usage and use of support organisations.

##### *4.1 Information provision*

The process of reaching a diagnosis for those with a specific and non-specific learning disability diagnosis warrants further investigation. The professional who provides the diagnosis is often the first source of information and therefore an important link to future information and support. The results from the current study suggest families' experience of diagnosis and information provision is extremely variable. If the NHS and other relevant agencies are to

improve the service provision for families with a child with a learning disability then further investigation of their needs relating to diagnosis and information provision is required. The current study looked at the amount of and satisfaction with the information families had received. The format of information provided has also been found to be important with regard to how well information is remembered and acted upon, with written information in conjunction with verbal information being better than verbal information alone (Johnson et al., 2003). There has been little research on information provision to families with a child with a learning disability. A future avenue for research could look at the format of information provided to families regarding their child's difficulties along with families' preferences for information format. Similarly the timing and source of the information has been found to be important in children with disabilities (Speedwell et al., 2003). This again could be looked at within the child learning disability population. Such research is needed if provision of information to these families is to improve.

#### *4.2 Learning disability terminology*

Similarly, the use of multiple terms to describe the same set of difficulties is an area that has potential for future research. Currently two key service providers, health and education use different terminology which does not aid communication with parents or between services. Health and social care mainly use the term learning disability in clinical practice and policy documents e.g. The same as you? (Scottish Executive, 2000), whereas education is moving away from using any labels at all e.g. the Education (Additional Support for Learning) (Scotland) Act 2004 which simply refers to 'additional support

needs'. The effects of having numerous labels for the same set of difficulties, particularly when a child has a non-specific learning disability diagnosis is yet to be extensively investigated. Furthermore families' preferences on whether their child has a label and the positive and negative consequences for families of their child having a learning disability diagnosis are areas of interest for future research.

A further consideration is the effect the Education (Additional Support for Learning) (Scotland) Act 2004 will have on researchers attempting to identify the child learning disability population. Also whether the Act will, as it is planned to, aid families in gaining appropriate support for their child or whether the lack of label will hinder access to some sources of support.

#### *4.3 Support organisations*

There has been little research on the use of support organisations by families with a child with a learning disability. The current study found that parents often found other parents to be useful sources of information and support. Groups run by organisations such as Down Syndrome Scotland are one way for parents to access this kind of support. Van Teijlingen, Friend & Kamal (2001) found that, with rarer physical diagnoses, support organisations often filled the gap in knowledge and support available to families from statutory services. Whilst this study looked at physical conditions there is also some evidence from the learning disability population. Carmichael et al. (1999) found that for some parents of children with a Fragile X diagnosis the UK Fragile X society was their best and at times only source of information. Thus accessibility to such



information and support from organisations is an important consideration for further research if the information and support families need are to be met.

### **Section five: Summary and conclusion**

The current study investigated whether families of children with a learning disability differed with regard to their experiences of information, support and parental stress according to whether their child had a specific or non-specific learning disability diagnosis. The relationship between information, support and stress was also explored. This was based on the research findings relating to the information provided to families, the impact of support available to these families and the parental stress experienced by this population.

In total 47 people participated in the current research, 23 whose child had a specific learning disability diagnosis and 24 whose child had a non-specific learning disability diagnosis. The main results were that the two groups differed with regard to the number of sources from which they had received information, but did not differ in either the amount of, or satisfaction with, information they had received. Significantly more of the specific diagnosis group had accessed a support organisation but there were no differences in the amount of or satisfaction with information received from support organisations by the two groups. There was no difference in the numbers of professionals available as support or satisfaction with this support between the two groups. There were also no differences between those whose child had a specific diagnosis and those whose child had a non-specific diagnosis with regard to parental stress.



There was found to be a relationship between some information and support variables however there was found to be no significant relationship between information, support and stress.

This indicates that parents with a child with a non-specific diagnosis may have access to fewer sources of information and support organisations than parents of children with a specific diagnosis. However if they are able to access information and support this is likely to be of the same quality regardless of specificity of learning disability diagnosis. This highlights that a key consideration is accessibility rather than quality of information and support for families with a child with a non-specific learning disability diagnosis. Parental stress does not appear to be dependent on specificity of learning disability diagnosis, possibly due to the many factors implicated in parental stress. Information and support alone do not appear to predict parental stress in families with a child with a learning disability. The current study found several limitations with regard to the information and support available to families of children with a learning disability and this area warrants further investigation.

## References

- Abbeduto, L., Seltzer, M.M., Shattuck, P., Krauss, M.W., Orsmond, G. & Murphy, M.M. (2004). Psychological well-being and coping in mothers of youths with Autism, Down syndrome or Fragile X syndrome. *American Journal on Mental Retardation*, 109(3), 237-254.
- American Association on Mental Retardation Definition of Mental Retardation, [www.aamr.org/Policies/faq\\_mental\\_retardation.shtml](http://www.aamr.org/Policies/faq_mental_retardation.shtml), accessed 6<sup>th</sup> June 2006.
- American Psychiatric Association (1994). *Diagnostic and Statistical Manual of Mental Disorders* (4<sup>th</sup> edn). Washington DC: American Psychiatric Association.
- Aminidav, C. & Weller, L. (1995). Effects of country of origin, sex, religiosity and social class on breadth of knowledge of mental retardation. *The British Journal of Developmental Disabilities*, 41(1), 48-56.
- Antonak, R. F., Fiedler, C.R. & Mulick, J.A. (1989). Misconceptions relating to mental retardation. *Mental Retardation*, 27(2), 91-97.
- Arvio, M. & Sillanpaa, M. (2003). Prevalence, aetiology and comorbidity of severe and profound intellectual disability in Finland. *Journal of Intellectual Disability Research*, 47(2), 108-112.
- Barr, O. (1999). Genetic counselling: a consideration of the potential and key obstacles to assisting parents to adapt to a child with learning disabilities. *British Journal of Learning Disabilities*, 27, 30-36.
- Beck, A., Hastings, R.P. & Daley, D. (2004). Pro-social behaviour and behaviour problems independently predict maternal stress. *Journal of Intellectual & Developmental Disability*, 29(4), 339-349.

- Bristol, M.M., Gallagher, J.J. & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: adaptation and spousal support. *Developmental Psychology*, 24(3), 441-451.
- British Psychological Society (2000). *Learning Disability: definitions and contexts*. Leicester: British Psychological Society.
- Cahill, B.M. & Glidden, L.M. (1996). Influence of child diagnosis on family and parental functioning: Down syndrome versus other disabilities. *American Journal on Mental Retardation*, 101(2), 149-160.
- Caine, A., Hatton, C. & Emerson, C. (1998). Service Provision. In E. Emerson, C. Hatton, J. Bromley & A. Caine (Eds.) *Clinical Psychology and People with Intellectual Disabilities* (pp.54-75). Chichester: John Wiley & Sons.
- Carmichael, B., Pembrey, M., Turner, G. & Barnicoat, A. (1999). Diagnosis of Fragile-X syndrome: the experience of parents. *Journal of Intellectual Disability Research*, 43(1), 47-53.
- Clark-Carter, D. (1997). *Doing quantitative research: from design to report*. Hove: Psychology Press.
- Cohen, J. (1992). A power primer. *Psychological Bulletin*, 112(1), 155-159.
- Coid, D.R. & Crombie, I.K. (2001). What do we know about the voluntary healthcare sector in Scotland? *Health Bulletin*, 59(4), 224-227.
- Coolican, H. (2004). *Research Methods and Statistics in Psychology* (4<sup>th</sup> edn). London: Hodder Arnold.
- Crookes, P.A. & Davies, S. (1998). *Research into Practice* (Eds.). London: Harcourt Brace & Co.

Cuskelly, M. & Gunn, P. (2003). Sibling relationships of children with Down syndrome: perspectives of mothers, fathers and siblings. *American Journal on Mental Retardation*, 108(4), 234-244.

Dickens, P. & Stallard, A. (1987) *Assessing Mentally Handicapped People: A guide for Care Staff*. Berkshire: NFER-Nelson.

Donovan, A.M. (1988). Family stress and ways of coping with adolescents who have handicaps: maternal perceptions. *American Journal on Mental Retardation*, 92(6), 502-509.

Dunst, C.J., Jenkins, V. & Trivette, C.M. (1984). The Family Support Scale: reliability and validity. *Journal of Individual, Family and Community Wellness*, 1, 45-52.

Dunst, C.J., Trivette, C.M. & Hamby, D.W. (1994). Family Support Scale. In C.J. Dunst, C.M. Trivette & A.G. Deal (Eds.) *Supporting strengthening Families, Volume 1: Methods, Strategies and Practices*. Cambridge: Brookline Books.

Dyson, L. (1993). Response to the presence of a child with disabilities: parental stress and family functioning over time. *American Journal on Mental Retardation*, 98(2), 207-218.

Dyson, L. (1997). Fathers and mothers of school-age children with developmental disabilities: parental stress, family functioning and social support. *American Journal on Mental Retardation*, 102(3), 267-279.

Eby, M. (1993). Validation: choosing a test to fit the design. *Nurse Researcher*, 1,(2), 26-32.

Eisenhower, A.S., Baker, B.L. & Blacher, J. (2005). Preschool children with intellectual disability: syndrome specificity, behaviour problems and maternal well-being. *Journal of Intellectual Disability Research*, 49(9), 657-671.

Emerson, E. (1998). Assessment. In E. Emerson, C. Hatton, J. Bromley & A. Caine (Eds.) *Clinical Psychology and People with Intellectual Disabilities* (pp.114-124). Chichester: John Wiley & Sons.

Emerson, E., Hatton, C., Bromley, J. & Caine, A. (1998). *Clinical Psychology and People with Intellectual Disabilities*. Chichester: John Wiley & Sons.

Emerson, E. (2003). Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research*, 47(4/5), 385-399.

Essex, E.L., Seltzer, M.M. & Krauss, M.W. (1999). Differences in coping effectiveness and well-being among aging mothers and fathers of adults with mental retardation. *American Journal on Mental Retardation*, 104(6), 545-563.

Fife-Shaw, C. (2000). Levels of measurement. In G.M. Breakwell, S. Hammond & C. Fife-Shaw (Eds.) *Research Methods in Psychology* (4<sup>th</sup> edn, pp.155-156). London: Sage Publications.

Frey, K.S., Greenberg, M.T. & Fewell, R.R. (1989). Stress and coping among parents of handicapped children: a multidimensional approach. *American Journal on Mental Retardation*, 94(3), 240-249.

Friedrich, W.N., Greenberg, M. & Crnic, K.A. (1983). A short form of the Questionnaire on Resources and Stress. *American Journal of Mental Deficiency*, 88, 41-48.

Friedrich, W.N., Wiltturner, L.T. & Cohen, D.S. (1985). Coping resources and parenting mentally retarded children. *American Journal of Mental Deficiency*, 90(2), 130-139.

Gates, B. (1997). What is learning disability: a question of semantics or political correctness? *Journal of Learning Disabilities for Nursing, Health and Social Care*, 1(2), 51-52.

Gattuso, J., Hinds, P., Tong, X. & Scrivasta, K. (2006). Monitoring child and parent refusals to enrol in clinical research protocols. *Journal of Advanced Nursing*, 53(3), 319-326.

Glidden, L.M. & Pursley, J.T. (1989). Longitudinal comparisons of families who have adopted children with mental retardation. *American Journal on Mental Retardation*, 94(3), 272-277.

Glidden, L.M. & Schoolcraft, S.A. (2003). Depression: its trajectory and correlates in mothers rearing children with intellectual disability. *Journal of Intellectual Disability Research*, 47, 250-263.

Gowen, J.W., Johnson-Martin, N., Goldman, B.D. & Appelbaum, M. (1989). Feelings of depressions and parenting competence of mothers of handicapped and nonhandicapped infants: a longitudinal study. *American Journal on Mental Retardation*, 94(3), 259-271.

Grant, G., Ramcharan, P., McGrath, M., Nolan, M. & Keady, J. (1998). Rewards and gratifications among family caregivers: towards a refined model of caring and coping. *Journal of Intellectual Disability Research*, 42(1), 58-71.

Gross, R. (1996). *Psychology: The Science of Mind and Behaviour* (3<sup>rd</sup> edn). London: Hodder & Stoughton.

- Hall, S. & Marteau, T.M. (2003). Causal attributions and blame: associations with mothers' adjustment to the birth of a child with Down syndrome. *Psychology, Health & Medicine*, 8(4), 415-423.
- Harris, V.S. & McHale, S.M. (1989). Family life problems, daily caregiving activities and the psychological well-being of mothers of mentally retarded children. *American Journal on Mental Retardation*, 94(3), 231-239.
- Hassall, R., Rose, J. & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: the effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, 49(6), 405-418.
- Hastings, R.P., Allen, R., McDermott, K. & Still, D. (2002a). Factors related to positive perceptions in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 269-275.
- Hastings, R.P., Thomas, H. & Delwiche, N. (2002b). Grandparent support for families of children with Down's syndrome. *Journal of Applied Research in Intellectual Disabilities*, 15, 97-104.
- Hatton, C. (1998). Intellectual disabilities- epidemiology and causes. In E. Emerson, C. Hatton, J. Bromley & A. Caine (Eds.) *Clinical Psychology and People with Intellectual Disabilities* (pp.20-38). Chichester: John Wiley & Sons.
- Hoare, P., Harris, M., Jackson, P. & Kerley, S. (1998). A community survey of children with severe intellectual disability and their families: psychological adjustment, carer distress and the effect of respite care. *Journal of Intellectual Disability Research*, 42(3), 218-227.
- Hodapp, R.M., Dykens, E.M. & Masino, L.L. (1997). Families of children with Prader-Willi syndrome: stress-support and relations to child characteristics. *Journal of Autism and Developmental Disorders*, 27(1), 11-24.



- Hodapp, R.M., Fidler, D.J. & Smith, A.C.M. (1998). Stress and coping in families of children with Smith-Magenis syndrome. *Journal of Intellectual Disability Research*, 42(5), 331-340.
- Holroyd, J. (1974). The Questionnaire on Resources and Stress: An instrument to measure family responses to a handicapped family member. *Journal of Community Psychology*, 2, 92-94.
- Johnson, A., Sandford, J. & Tyndall, J. (2003). Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home. *The Cochrane Database of Systematic Reviews*, Issue 4, Art No: CD003716. DOI: 10.1002/14651858. CD003716.
- Kaufman, A.S. & Lichtenberger, E.O. (1999). *Essentials of the WAIS- III Assessment*. New York: Wiley.
- Kim, H.W., Greenberg, J.S., Seltzer, M.M. & Krauss, M.W. (2003). The role of coping in maintaining the psychological well-being of mothers of adults with intellectual disability and mental illness. *Journal of Intellectual Disability Research*, 47, 313-327.
- Krauss, M.W. (1993). Child-related and parenting stress: similarities and differences between mothers and fathers of children with disabilities. *American Journal on Mental Retardation*, 97(4), 393-404.
- Kwai-sang Yau, M. & Li-Tsang, C.W.P. (1999). Adjustment and adaptation in parents of children with developmental disability in two-parent families: a review of the characteristics and attributes. *The British Journal of Developmental Disabilities*, 45(1), 38-51.
- Leino-Kilpi, H., Iire, L., Suominen, T., Vuorenheimo, J. & Valimaki, M. (1993). Client and information: a literature review. *Journal of Clinical Nursing*, 2, 331-340.



Lennox, N.G., Diggins, J.N. & Ugoni, A.M. (1997). The general practice care of people with intellectual disability: barriers and solutions. *Journal of Intellectual Disability Research*, 41(5), 380-390.

Levy, J.M., Rimmerman, A., Botuck, S., Ardito, M., Freeman, S.E. & Levy, P.H. (1996). The support network of mothers of younger and adult children with mental retardation and developmental disabilities receiving case management. *The British Journal of Developmental Disabilities*, 42(1), 24-31.

Lezak, M.D., Howieson, D.B., Loring, D.W., Hannay, H.H. & Fischer, J.S. (2004). *Neuropsychological Assessment* (4<sup>th</sup> edn). New York: Oxford University Press.

Maxwell, V. (1993). Look through the parents' eyes: helping parents of children with a learning disability. *Professional Nurse*, 9(3), 200-203.

Maxwell, V. & Barr, O. (2003). With the benefit of hindsight: a mother's reflections on raising a child with Down syndrome. *Journal of Learning Disabilities*, 7(1), 51-64.

McIntyre, L.L., Blacher, J. & Baker, B.L. (2002). Behaviour/mental health problems in young adults with intellectual disability: the impact on families. *Journal of Intellectual Disability Research*, 46(3), 239-249.

McKay, C. (1991). *Sex, Laws and Red Tape: Scots Law, personal Relationships and People with Learning Disabilities*. Glasgow: Scottish Society for the Mentally Handicapped.

McKenzie, K., Murray, G., Matheson, E., Higgon, J. & Sinclair, B. (1999a). What is learning disability? Do people need to be reminded? *Learning Disability Practice*, 2(1), 8-11.

McKenzie, K., Paxton, D., Murray, G.C., Matheson, E. & McCaskie, K. (1999b). Misconceptions about learning disability. *Scottish Medicine*, 18(3), 4-5.

McKenzie, K., Paxton, D., Murray, G.C. & Matheson, E. (2000). Professional composition of community learning disability teams: implications for service provision. *Health Bulletin*, 58(3); 192-197.

McLaren, J. & Bryson, S.E. (1987). Review of recent epidemiological studies of mental retardation: prevalence, associated disorders and etiology. *American Journal of Mental Retardation*, 92(3), 243-254.

National Autistic Society (2006). *What are the Characteristics of Autism?* [www.nas.org.uk/nas/jsp/polopoly.jsp?d=211](http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=211), accessed 16<sup>th</sup> May 2006.

NHS Quality Improvement Scotland (2004). *Learning Disabilities Quality Indicators*. Edinburgh: NHS Quality Improvement Scotland.

Nunkoosing, K. (1995). Learning disability: Psychology's contribution to diagnosis, assessment and treatment. In R. Bull & D. Carson (Eds.) *Handbook of Psychology in Legal Contexts*, Chichester: John Wiley & Sons.

Quine, L. & Rutter, D.R. (1994). First diagnosis of severe mental and physical disability: a study of doctor-parent communication. *Journal of Child Psychology and Psychiatry*, 35(7), 1273-1287.

Rendall, D. (1997). Fatherhood and learning disabilities: personal account of reaction and resolution. *Journal of Learning Disabilities for Nursing, Health and Social Care*, 1(2), 77-83.

Ricci, L.A. & Hodapp, R.M. (2003). Fathers of children with Down's syndrome versus other types of intellectual disability: perceptions, stress and involvement. *Journal of Intellectual Disability Research*, 47, 273-284.

- Roach, M.A., Orsmond, G.I. & Barratt, M.S. (1999). Mothers and fathers of children with Down syndrome: parental stress and involvement in childcare. *American Journal on Mental Retardation*, 104(5), 422-436.
- Rousey, A., Best, S. & Blacher, J. (1992). Mothers' and fathers' perceptions of stress and coping with children who have severe disabilities. *American Journal on Mental Retardation*, 97(1), 99-109.
- Saloviita, T., Itälä, M. & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a double ABCX model. *Journal of Intellectual Disability Research*, 47, 300-312.
- Sanders, J.L. & Morgan, S.B. (1997). Family stress and adjustment as perceived by parents of children with Autism or Down syndrome: implications for intervention. *Child and Family Behavior Therapy*, 19(4), 15-32.
- Scott, R.L., Sexton, D., Thompson, B. & Wood, T.A. (1989). Measurement characteristics of a Short-Form of the Questionnaire on Resources and Stress. *American Journal on Mental Retardation*, 94, 331-339
- Scottish Executive (2000). *The same as you? A review of services for people with learning disabilities*, HMSO: Edinburgh.
- Scottish Executive (2004). *Education (Additional Support for Learning) (Scotland) Act*, The Stationary Office Ltd: Edinburgh
- Scriven, A. & Tucker, C. (1997). The quality and management of written information presented to women undergoing hysterectomy. *Journal of Clinical Nursing*, 6(2), 107-113.
- Sharrad, H. (1992) Feeling the strain: Job stress and satisfaction of direct care staff in the mental handicap service. *The British Journal of Mental Subnormality*, 38(1), 32-38.

Sherman, S.L., Jacobs, P.A., Morton, N.E., Froster-Iskenius, U., Howard-Peebles, P.N., Nielsen, K.B., Partington, M.W., Sutherland, G.R., Turner, G. & Watson, M. (1985). Further segregation analysis of the Fragile X syndrome with special reference to transmitting males. *Human Genetics*, 69, 289-299.

Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (1984). *Vineland Adaptive Behaviour Scales*. Circle Pines, MN: American Guidance Service.

Speedwell, L., Stanton, F. & Nischal, K.K. (2003). Informing parents of visually impaired children: who should do it and when? *Child: Care, Health and Development*, 29(3), 219-224.

Stanley, B. & Roy, A. (1988). Evaluating the quality of life of people with mental handicaps: A social validation study. *Mental Handicap Research*, 1 (2), 197-210.

Thomson, M. (1996). Family, community and state: the micro-politics of mental deficiency. In D. Wright & A. Digby (Eds.) *From Idiocy to Mental Deficiency* (pp.207-230). London: Routledge.

van Riper, M. (1999). Maternal perceptions of family-provider relationships and well-being in families of children with Down syndrome. *Research in Nursing & Health*, 22, 357-368.

van Teijlingen, E.R., Friend, E. & Kamal, A. (2001). Service use and needs of people with motor neurone disease and their carers in Scotland. *Health & Social Care in the Community*, 9(6), 397-403.

Wechsler, D. (1997). *Wechsler Adult Intelligence Scale- Third Edition*. San Antonio, TX: The Psychological Corporation.

Wellesley, D., Hockey, A. & Stanley, F. (1991). The aetiology of intellectual disability in Western Australia: a community based study. *Developmental Medicine and Child Neurology*, 33, 963-973.

Whitaker, S. (2004). Hidden learning disability. *British Journal of Learning Disabilities*, 32, 139-143.

Withers, P. & Bennett, L. (2003). Myths and marital discord in a family with a child with profound physical and intellectual disabilities. *British Journal of Learning Disabilities*, 31, 91-95.

York, A., von Fraunhofer, N., Turk, J. & Sedgwick, P. (1999). Fragile-X syndrome, Down's syndrome and autism: awareness and knowledge amongst special educators. *Journal of Intellectual Disability Research*, 43(4), 314-324.

## **Appendix I: Definitions of learning disability/mental retardation**

The definition given by the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders, (DSM-IV) has the three criteria of

- “significantly subaverage intellectual functioning: an IQ of approximately 70 or below”
- “concurrent deficits or impairments in present adaptive functioning”
- “the onset is before age 18 years” (APA, 1994).

The American Association on Mental Retardation (AAMR) defines mental retardation as a:

“disability characterised by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills” (AAMR, [www.aamr.org/Policies/faq\\_mental\\_retardation.shtml](http://www.aamr.org/Policies/faq_mental_retardation.shtml), accessed 6<sup>th</sup> June 2006).

The AAMR also states that the disability must originate before the age of 18.

## **Appendix II: Systematic review of literature used in the introduction**

The majority of references cited in the introduction were included in the systematic review. However some sources could not be systematically reviewed due to being a policy document, book, professional body or a journal article that was not experimental in design.

## Systematic Review

\*Effect size calculated with reference to Cohen (1992)

Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Abbeduto, Seltzer, Shattuck, Krauss, Orsmond & Murphy (2004)	Psychological well-being and coping in mothers of youths with autism, down syndrome or fragile x syndrome	Differences in psychological well-being and coping in mothers of children from different diagnostic groups	<ul style="list-style-type: none"> <li>- Inclusion of Fragile X</li> <li>- Consideration of factors relating to diagnosis</li> <li>- Numerous methods of recruitment</li> </ul>	<ul style="list-style-type: none"> <li>- Very disparate numbers in each group</li> <li>- Only considered autistic behaviours when looking at problem behaviour</li> </ul>	Maternal psychological well-being different for each diagnostic group: Downs>Fragile X>Autism. Behaviour biggest predictor of maternal outcomes	Medium/large depending on difference looked at	USA
Aminidav & Weller (1995)	Effects of country of origin, sex, religiosity and social class on breadth of knowledge of mental retardation	The effect of socio-cultural factors on knowledge and understanding of learning disability	<ul style="list-style-type: none"> <li>-Consideration of cultural factors</li> <li>-Large sample</li> </ul>	<ul style="list-style-type: none"> <li>-Generalisability of Israeli results to UK population?</li> <li>-Whilst different country of origin all participants were Jewish</li> </ul>	Individuals of Western origin had more accurate knowledge than those of Eastern origin as did those from middle class backgrounds compared to lower social class.	N/A	Israel



Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Antonak, Fiedler & Mulick (1989)	Misconceptions relating to mental retardation	Comparison of endorsement of misconceptions between current study and earlier study plus effects of professional training, occupation and contact with people with mental retardation on knowledge	<ul style="list-style-type: none"> <li>-Large sample</li> <li>-Comparison of attitudes over time</li> <li>-inclusion of effect of knowing people with mental retardation on understanding</li> </ul>	<ul style="list-style-type: none"> <li>-Limited to set misconceptions and thus other false beliefs relating to LD not considered</li> <li>-Understanding of the term mental retardation not assessed</li> </ul>	<ul style="list-style-type: none"> <li>-Fewer misconceptions were endorsed in 1986 than 1956</li> <li>-Professional training, occupation and previous contact with LD population influenced endorsement of misconceptions</li> </ul>	Medium	USA
Arvio & Sillanpaa (2003)	Prevalence, aetiology and comorbidity of severe and profound intellectual disability in Finland	Prevalence and aetiology	<ul style="list-style-type: none"> <li>-Aetiological and background factors studied</li> <li>-Large sample for looking at aetiology</li> <li>-Agreed with previous estimates for Finland and similar to Norway statistics</li> <li>-Northern European study</li> </ul>	<ul style="list-style-type: none"> <li>-One area of Finland-generalisable to other parts of Finland and beyond?</li> </ul>	Prevalence of severe of profound learning disability similar to those in other European studies. Aetiology for majority was genetic or congenital	N/A	Finland

Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Barr (1999)	Genetic counselling: a consideration of potential & key obstacles to assisting parents adapt to a child with learning disabilities	Consideration of advantages and disadvantages of genetic counselling in helping parents adjustment	<ul style="list-style-type: none"> <li>- Positive and negative aspects of genetic counselling considered</li> <li>- Links to service and research developments</li> </ul>	-Considers theoretical aspects and limited research but no new data	Genetic counselling doesn't always have positive outcome particularly where no genetic cause is found	N/A	UK
Beck, Hastings & Daley (2004)	Pro-social behaviour and behaviour problems independently predict maternal stress	Impact of child behaviour on maternal stress	<ul style="list-style-type: none"> <li>- UK study</li> <li>- Five standardised measures</li> <li>- Comparison to UK normative data</li> <li>-Reported results that didn't support previous findings</li> </ul>	<ul style="list-style-type: none"> <li>-Recruitment partly through parenting groups and tendency towards mothers who were coping well</li> <li>-Representative sample re: social class questionable</li> </ul>	Child behaviour problems are positive predictor of maternal stress and pro-social behaviour is negative predictor of maternal stress	Large	UK

Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Bristol, Gallagher & Schopler (1988)	Mothers and fathers of young developmentally disabled and non-disabled boys: adaptation and spousal support	Impact of child with a developmental disability on adaptation and family roles	<ul style="list-style-type: none"> <li>-Matched on child age, race, gender, parental marital status, age and socioeconomic status</li> <li>-Observations plus standardised questionnaires</li> </ul>	<ul style="list-style-type: none"> <li>-Relatively small sample</li> <li>-Two-parent, white families</li> <li>-Only parents of boys included</li> </ul>	Fathers were less involved in child-care in families with a child with a LD this was specific to the child with a LD not siblings and was related to severity of behaviour problems	N/A	USA
Cahill & Glidden (1996)	Influence of child diagnosis on family and parental functioning: down syndrome versus other disabilities	Stereotype of children with Downs syndrome being easier to raise than children with different diagnoses-questioned	<ul style="list-style-type: none"> <li>- Use of well-matched sample controlling for child level of functioning, child age, marital status and family income</li> <li>- 3 standardised measures</li> </ul>	- Relatively small sample size	<p>When matched for level of child functioning, child age, parental marital status and family income there was no difference in parental functioning between parents of children with Downs syndrome and children with other disabilities</p> <p>Looking for lack of difference between groups-effect size approaching 0</p>		USA

Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Carmichael, Pembrey, Turner & Barnicoat (1999)	Diagnosis of fragile-X syndrome: the experiences of parents	Experiences of the diagnostic process	-UK study -Large sample from across UK -Links to service improvement	-Recruited through fragile-X society ?biased sample	Parents have varying experiences of diagnosis with a considerable number receiving a poor service	N/A	UK
Cuskelly & Gunn (2003)	Sibling relationships of children with Down syndrome: perspectives of mothers, fathers and siblings	Comparison of sibling relationships with reference to kindness, empathy and caregiving in families with and without a Downs syndrome child	-Relatively large sample -Matched on child and family characteristics -Data from five interviews with each family averaged	-All families two-parent -Mainly middle class	Siblings of a child with Downs syndrome participated in more caregiving and reported less unkindness in the sibling relationship.	Medium	Australia
Donovan (1988)	Family stress and ways of coping with adolescents who have handicaps: maternal perceptions	Factors relating to maternal stress and coping in families with a child with ASD or learning disability	-Well matched groups on demographic variables -Use of three standardised measures	-Exclusion of one-parent families -Restriction to only two ethnic groups	Mothers of adolescents with ASD perceived greater levels of family stress than mothers of adolescents with mental retardation.	N/A	USA

Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Dyson (1993)	Response to the presence of a child with disabilities: parental stress and family functioning	Comparison of parental stress and family functioning in families with a child with/without a learning disability over time	- Follow-up to earlier study = longitudinal - Matched for child age and socio-economic status - Canada + USA	- Majority white middle class participants - Differences in maternal education level between groups	- Parental stress and family functioning stable over time in both groups - Greater stress levels in parents of children with a disability	Large	UK
Dyson (1997)	Fathers and mothers of school-age children with developmental disabilities: parental stress, family functioning and social support	Differences in parental stress between families with a disabled child and those with a non-disabled child	- Recruited from two countries (Canada & USA) - Three standardised measures - Completed individually by mothers and fathers	- Relatively small sample size - All married - All middle-class	Parents of children with developmental disabilities experienced greater stress in relation to their child than parents of children without disabilities	Large	USA/ Canada
Eisenhower, Baker & Blacher (2005)	Preschool children with intellectual disability: syndrome specificity, behaviour problems and maternal well-being	Relationships between different diagnoses, behaviour problems and maternal stress	- Recruited through state services - consideration of four different learning disability diagnoses and typically developing	- Despite large sample very uneven numbers in groups - Differences between groups in socio-economic factors	Children with autism and cerebral palsy had most behaviour problems. Mothers of children with autism reported the most parenting stress	Large	USA

Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Emerson (2003)	Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status and the self-assessed social and psychological impact of the child's difficulties	Secondary analysis of large data set gained from office for national Statistics survey	-Large data set -Several key areas covered -Random sample	-Secondary analysis means data not gathered with this analysis as main objective	Families with a child with a learning disability were significantly economically disadvantaged.	N/A	UK
Essex, Seltzer & Krauss (1999)	Differences in coping effectiveness and well-being among aging mothers and fathers of adults with mental retardation	Comparison of the use of problem-focused and emotion-focused coping strategies in mothers and fathers	- Large sample size - Longitudinal - Use of interviews and standardised questionnaires	-Majority white participants - coping measure not specific to child but coping in general	Mothers used more problem-focused coping than fathers and for mothers this was associated with better psychological well-being	Medium	USA

Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Frey, Greenberg & Fewell (1989)	Stress and coping among parents of handicapped children: a multidimensional approach	Relationships between child characteristics, social network, beliefs and coping styles to parents psychological well-being	<ul style="list-style-type: none"> <li>- Inclusion of mothers and fathers</li> <li>- Use of several standardised measures</li> <li>- Links to possible interventions</li> </ul>	<ul style="list-style-type: none"> <li>-cross-sectional</li> <li>-paid participants</li> </ul>	Child characteristics predicted parenting stress, parental beliefs predicted parenting stress, psychological distress & family adjustment, coping styles predicted psychological distress	Large	USA
Friedrich, Wiltner & Cohen (1985)	Coping resources and parenting mentally retarded children	Adequacy of coping resources as measured by a measure of family stress	<ul style="list-style-type: none"> <li>-Large Sample</li> <li>-Detailed analysis</li> <li>-10 month follow-up re-evaluation</li> </ul>	<ul style="list-style-type: none"> <li>-Only mothers</li> <li>-Majority well-educated and middle class</li> </ul>	Severity of disability related to parent and family problems. Coping resources good predictor of parental functioning	N/A	USA
Glidden & Pursley	Longitudinal comparisons of families who have adopted children with mental retardation	Adjustment in families who have adopted a child with a learning disability	<ul style="list-style-type: none"> <li>-Longitudinal study</li> <li>-Rarely considered area studied</li> </ul>	-Relatively small sample size	Good adjustment in majority of families who adopt a child with a learning disability	N/A	USA



Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Glidden & Schoolcraft (2003)	Depression: its trajectory and correlate in mothers rearing children with intellectual disability	Depression in both birth and adoptive mothers of children with a LD over time	<ul style="list-style-type: none"> <li>- Longitudinal</li> <li>- Large sample</li> <li>- Adoptive and birth mothers</li> <li>- Recruited through several different sources</li> <li>- Semi-structured interview plus standardised questionnaires</li> </ul>	<ul style="list-style-type: none"> <li>- Majority white</li> <li>- Majority middle-class</li> <li>- Personality measure only done on one occasion-</li> <li>assumption of stability</li> </ul>	Depression high at time of diagnosis for birth mothers but relatively low for both birth and adoptive mothers over time	Medium	USA
Gowen, Johnson-Martin, Goldman & Appelbaum (1989)	Feelings of depression and parenting competence of mothers of handicapped and nonhandicapped infants: longitudinal study	Relationship between maternal depression, feelings of parenting competence, child characteristics and social support: comparison of mothers of children with and without disability	<ul style="list-style-type: none"> <li>- Longitudinal-</li> <li>measures at several time points</li> <li>- Several standardised measures</li> </ul>	<ul style="list-style-type: none"> <li>- Small sample</li> <li>- Mothers only</li> </ul>	No difference on measures of maternal depression and feelings of parenting competence. For those with a child with a disability caregiving difficulty predicted maternal depression	No significant difference	USA



Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Grant, Ramcharan, McGrath, Nolan & Keady (1998)	Rewards and gratifications among family caregivers: towards a refined model of caring and coping	Rewards and gratifications associated with caregiving and the sources of these	-UK study -Large sample -Data from more than one source -Inclusion of positive as well as negative experiences	-Results mostly frequency data -No detailed analysis of the large amount of qualitative data	Caregivers report rewards of the caregiving experience as well as stresses. Rewards stem from interpersonal and intrapersonal factors	N/A	UK
Hall & Marteau (2003)	Causal attributions and blame: associations with mothers' adjustment to the birth of a child with Down syndrome	Relationships between attributions, blame and maternal adjustment	- UK study -Large sample -Random sample from a national register -Semi-structured interview plus standardised questionnaires	-Difficult concepts to measure: blame and attributions -Very brief results section	Blaming others was associated with poorer adjustment than those who made causal or no attributions.	Medium	UK
Harris & McHale (1989)	Family life problems, daily caregiving activities, and the psychological well-being of mothers of mentally retarded children	Comparison of mothers of children with and without a learning disability with regard to caregiving and well-being of mothers	-Recruited through state services for children with a learning disability -Matched on child age and gender along with socioeconomic factors	-Relatively small sample -Interviews and telephone contact-social desirability effects?	No overall differences in well-being. Main family problems for those with a child with a LD were child welfare issues and restrictive time demands	No significant difference	USA

Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Hassall, Rose & McDonald (2005)	Parenting stress in mothers of children with an intellectual disability: the effects of parental cognitions in relation to child characteristics and family support	Parental cognitions with particular reference to locus of control and its relation to parenting stress	<ul style="list-style-type: none"> <li>- UK study</li> <li>- Recruited through special schools</li> <li>- 6 standardised measures</li> <li>- Clear methodology</li> </ul>	<ul style="list-style-type: none"> <li>- Majority rural and middle class</li> <li>- Fathers not included</li> </ul>	Parental locus of control and child behaviour difficulties impact on parenting stress	Large	UK
Hastings, Allen, McDermott & Still (2002)	Factors related to positive perceptions in mothers of children with disabilities	Relationships between positive perceptions and mother and child demographics and maternal coping strategies	<ul style="list-style-type: none"> <li>- UK study</li> <li>- Focus on positive impact of child with a LD</li> <li>- Recruited through special schools</li> </ul>	<ul style="list-style-type: none"> <li>- Small sample</li> <li>- Exclusion of fathers</li> </ul>	Reframing coping strategies associated with perceiving child as source of happiness/fulfilment and family closeness	N/A	UK
Hastings, Thomas & Delwiche (2002)	Grandparent support for families of children with Down's Syndrome	The effect of grandparent support and conflict on parental stress	<ul style="list-style-type: none"> <li>- UK study</li> <li>- Inclusion of grandparents in LD family research</li> <li>- Consideration of positive and negative impact</li> </ul>	<ul style="list-style-type: none"> <li>- Low response rate may have implications for how representative sample is of population</li> </ul>	Grandparent support had positive impact on stress but grandparent conflict was significantly associated with increased stress	Medium-Large	UK

Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Hoare, Harris, Jackson and Kerley (1998)	A community survey of children with severe intellectual disability and their families: psychological adjustment, carer distress and the effect of respite care	Relationships between child characteristics, child psychiatric morbidity, carer distress and use of respite care	-UK study (Scottish) -Sample drawn from regional register of those diagnosed -large sample		Overall distress not very different from general population, however, carer distress associated with increased disability in child and respite use.	N/A	UK
Hodapp, Dykens & Masino (1997)	Families of children with Prader-Willi Syndrome: stress-support and relations to child characteristics	Stress and available support in families of children with Prader-Willi syndrome	-Study of rarer diagnostic group -Consideration of who provides support to families	-Recruited through parent groups suggestive that sample are those who can access support -Use of three standardised measures	Parents of children with Prader-Willi syndrome reported higher levels of parent and family problems than families of children with other LD diagnoses Families of children with Prader-Willi reported family and friends as their main source of support.	N/A	USA

Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Hodapp, Fiedler, & Smith (1998)	Stress and coping in families of children with Smith-Magenis syndrome	Stress, in relationship to child's level of impairment and family support in a specific diagnostic group	-Use of five standardised measures -Little studied population	-Recruited through parents researchers group -Majority middle class	As with other diagnoses degree of impairment and maladaptive behaviour predicted stress also for this group number of family friends found to be mediating factor in stress	Medium	USA
Kim, Greenberg, Seltzer & Krauss (2003)	The role of coping in maintaining the psychological well-being of mothers of adults with intellectual disability and mental illness	Comparison of coping in mothers with children with a learning disability or mental illness	-Large sample -Matched for maternal age and adult child living at home -Data from two time points	-Very different numbers in each group -Data taken from separate studies looking at mental illness and learning disability not initially designed to tackle current research question	For both groups emotion focused coping was associated with decline in well-being. Increase in problem focussed coping was associated with improved quality of life for mothers if children with a learning disability	N/A	USA

Author & Date	Title	Area Investigated	Pros	Cons	Main Results	Effect Size*	Nationality of study
Krauss (1993)	Child-related and parenting stress: similarities and differences between mothers and fathers of children with disabilities	Differences in sources and predictors of stress for mothers and fathers	<ul style="list-style-type: none"> <li>-Sample of over 100</li> <li>-Data from larger longitudinal study with detailed data</li> <li>-3 parent measures plus assessment of child's ability</li> </ul>	<ul style="list-style-type: none"> <li>-All married</li> <li>-Children all preschool -greater stress when child older?</li> </ul>	Fathers reported more stress in relationship to child temperament and relationship with child. Mothers reported more stress related to personal consequences of parenting a child with a disability.	Small/ Medium depending on difference looked at	USA
Kwai-sang Yau & Li-Tsang (1999)	Adjustment and adaptation in parents of children with developmental disability in two-parent families: a review of the characteristics and attributes	Review of 20 years of literature on adjustment and adaptation in families with a child with developmental disability	<ul style="list-style-type: none"> <li>-Review of 70 papers</li> <li>-Consideration of several areas impacting on adaptation and adjustment</li> </ul>	<ul style="list-style-type: none"> <li>-Descriptive rather than critical</li> <li>-Relatively recent although seven years since publication-relevant research will have been conducted since</li> </ul>	Two-parent families with few children, high socio-economic status, resources to cope with crisis and supportive community are associated with ability to cope with stress of rearing a child with developmental disability	N/A	Hong-Kong

Author & Date	Title	Area Investigated	Pros	Cons	Main Results	Effect Size*	Nationality of study
Leino-Kilpi, Iire, Suominen, Vuorenheimo & Valimaki (1993)	Client and information: a literature review	Review of literature regarding patient information	<ul style="list-style-type: none"> <li>-Review of information literature</li> <li>-Consideration of different patient groups</li> </ul>	<ul style="list-style-type: none"> <li>-Does not cover the LD population</li> </ul>	Information usually beneficial can help cope with health difficulties and stress	N/A	Finland
Levy, Rimmerman, Botuck, Ardito, Freeman & Levy (1996)	The support network of mothers of younger and adult children with mental retardation and developmental disabilities receiving case management	Support networks- degree of involvement of family and professionals and helpfulness of this support	<ul style="list-style-type: none"> <li>-Relatively large sample</li> <li>-Inclusion of younger and adult children, different diagnoses and cultural backgrounds</li> </ul>	<ul style="list-style-type: none"> <li>-Only one measure of support-adapted from standardised measure</li> </ul>	<ul style="list-style-type: none"> <li>-Mothers relied more and professional supports and rated these as more helpful than family supports</li> </ul>	N/A	USA
McIntyre, Blacher & Baker (2002)	Behaviour/mental health problems in young adults with intellectual disability: the impact on families	Relationships between adaptive functioning, maladaptive behaviour, mental health problems and negative impact on family	<ul style="list-style-type: none"> <li>-Large sample</li> <li>-Links to service provision</li> <li>-Several standardised measures</li> </ul>	<ul style="list-style-type: none"> <li>-Majority European-American</li> <li>-Majority married with some college education</li> <li>-Only mothers responses</li> </ul>	Behaviour and mental health problems predicted mothers perceived negative impact on family	Large	USA

Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
McKenzie, Murray, Matheson, Higgon & Sinclair (1999)	What is learning disability?	Health and care professionals knowledge of what learning disability means	<ul style="list-style-type: none"> <li>-UK study</li> <li>-Variety of health and care staff surveyed</li> <li>-Random sample</li> <li>-Sample drawn from a range of different services</li> </ul>	<ul style="list-style-type: none"> <li>-Relatively small sample</li> </ul>	Health and care staff including GPs had relatively low levels of knowledge regarding the three core criteria of a learning disability	N/A	UK
McLaren & Bryson (1987)	Review of recent epidemiological studies of mental retardation: prevalence, associated disorders and aetiology	Review of studies looking at prevalence and aetiology	<ul style="list-style-type: none"> <li>-Reviewed studies from several different countries</li> <li>-21 prevalence studies</li> </ul>	<ul style="list-style-type: none"> <li>-Age of paper-relevant research has since been conducted</li> <li>-Difficulties with differing definitions used in reviewed studies</li> </ul>	Prevalence of a learning disability 3 to 4 per thousand, cause unknown for up to 50%	N/A	Canada
Quine & Rutter	First diagnosis of severe mental and physical disability: a study of doctor-parent communication	Parents experiences of being told of their child's diagnosis and their satisfaction with the process	<ul style="list-style-type: none"> <li>-UK study</li> <li>-Large sample</li> <li>-Consideration of different diagnoses</li> </ul>	<ul style="list-style-type: none"> <li>-From only one part of UK (south east England)</li> </ul>	High levels of dissatisfaction amongst patients particularly related to length of wait prior to diagnosis	N/A	UK



Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Rendall (1997)	Fatherhood and learning disabilities: a personal account of reaction and resolution	Fathers' experiences of having a child with a learning disability	<ul style="list-style-type: none"> <li>-UK Study</li> <li>-Mix of personal reflections with research data</li> <li>-Use of semi-structured interview and questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>-Convenience sample</li> <li>-No knowledge of social factors of participants</li> </ul>	Fathers experience the same shock, disbelief and devastation to mothers on learning of child's diagnosis. Need for inclusion of fathers in research/support/interventions	N/A	UK
Ricci & Hodapp (2003)	Fathers of children with Down's syndrome versus other types of intellectual disability: perceptions, stress and involvement	Impact of diagnosis and child personality on parental stress	<ul style="list-style-type: none"> <li>-Controlled for education level</li> <li>-Use of five standardised measures</li> <li>-Focus on fathers</li> </ul>	<ul style="list-style-type: none"> <li>-Relatively small sample</li> <li>-Groups not matched for ethnicity or education level</li> </ul>	Fathers of children with Down syndrome perceived their child to have more positive personality traits, fewer maladaptive behaviours plus less child-related stress than fathers of children with other types of intellectual disability	Medium	USA



Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Roach, Orsmond & Barratt (1999)	Mothers and fathers of children with Down syndrome: parental stress and involvement in child care	Comparison of stress and involvement of parents with a child with Downs syndrome and those with typically developing children	-Mothers and fathers completed survey -Socio-economic status matched	-Differences in child and parental ages between groups -All were two-parent families	Parents of children with Downs syndrome reported more caregiving difficulties, child-related stress and parent-related stress.	Large	USA
Rousey, Best & Blacher (1992)	Mothers' and fathers' perceptions of stress and coping with children who have severe disabilities	Comparison of mothers and fathers self-report of stress and coping	-Inclusion of fathers	-Predominantly white and middle class	Little difference between mothers' and fathers' scores on self-report measure with exception of pessimism with mothers reporting significantly more.	No difference on most subscales thus effect size approaching zero	USA

Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Saloviita, Italinna & Leinonen (2003)	Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a double ABCX model	Component analysis of factors relating to stress in parents of a child with a learning disability	<ul style="list-style-type: none"> <li>-Large sample</li> <li>-Mothers and fathers</li> <li>-Use of measure answered individually by mother and father and together</li> </ul>	<ul style="list-style-type: none"> <li>-Restricted age range of children for full analysis</li> <li>-One-parent families excluded</li> </ul>	Negative definition of situation most important predictor of stress. Negative definition associated with different factors for mothers and fathers	Large	Finland
Sanders & Morgan (1997)	Family stress and adjustment as perceived by parents of children with autism or down syndrome: implication for intervention	Comparison of parental stress and adjustment in parents of children with different diagnoses	<ul style="list-style-type: none"> <li>- Specificity of diagnosis assessed by independent health professional</li> <li>- Reading difficulties controlled for by reading out of two standardised measures</li> </ul>	<ul style="list-style-type: none"> <li>-Small sample size</li> <li>- Unclear if groups matched on social factors</li> <li>- Limited age range of children</li> <li>-Impact of social desirability due to answers being told to interviewer so not totally anonymous</li> </ul>	Differences in family stress and adjustment problems between diagnostic groups: Autism>Downs syndrome > developmentally normal	Large	USA

Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Wellesley, Hockey & Stanley (1991)	The aetiology of intellectual disability in Western Australia: a community-based study	Examination of prevalence of different causes of learning disability	<ul style="list-style-type: none"> <li>-Large sample (over 1000)</li> <li>-Detailed examination of different causes</li> <li>-Recruitment through several sources</li> </ul>		Pre-natal causes were the most common, with chromosomal disorders being the most common of these causes. A significant proportion of people have unknown aetiology for their learning disability	N/A	Australia
Whitaker (2004)	Hidden Learning Disability	Consideration of the population that meets criteria for learning disability and the population that receives learning disability services	<ul style="list-style-type: none"> <li>-Consideration of the disparity of those meeting criteria and those receiving services- links to service planning</li> <li>-Consideration of the need for LD to always be identified</li> </ul>	-Assumption that findings for one part of the country can be generalised to wider UK	Only a small proportion of these who meet criteria for learning disability are known to services	N/A	UK

Author & Date	Title	Area Investigated	Strengths	Weaknesses	Main Results	Effect Size*	Nationality of study
Withers & Bennett (2003)	Myths and marital discord in a family with profound physical and intellectual disabilities	Case study of family and role of services in supporting them in caring for severely disabled child	<ul style="list-style-type: none"> <li>-Illustrative of effects on marital and family relationships of caring for severely disabled child</li> <li>-Highlights importance of role of professionals in supporting families appropriately</li> </ul>	<ul style="list-style-type: none"> <li>-Case study so not necessarily representative</li> <li>-UK based</li> </ul>	Caring for a child with severe disabilities can have major impact on family relations and professional services do not always meet their needs	N/A	UK
York, von Fraunhofer, Turk & Sedgwick (1999)	Fragile-X syndrome, Down's syndrome and autism: awareness and knowledge amongst special educators	Investigation of school staff's knowledge regarding the three different diagnoses and their implications for education	<ul style="list-style-type: none"> <li>-Large sample size</li> <li>-UK study</li> <li>-comparison of special school and mainstream staff</li> </ul>	<ul style="list-style-type: none"> <li>-Possibility of staff using resources such as books to answer questions</li> </ul>	Majority of special and mainstream staff had some knowledge of main features of Downs syndrome and Autism few knew about key features of Fragile X and implications for education	N/A	UK

Effect size was calculated where possible with reference to Cohen (1992). However for several studies this was not possible either due to there not being enough information to do the calculation or numerous statistical analyses of several key differences and thus being unable to calculate an overall effect size for the main result of the study.

**Appendix III: Demographic, diagnosis and information questionnaire**

Age of child .....

Does your child have a specific diagnosis e.g. Down's Syndrome or Autistic Spectrum Disorder (please tick)

Yes

☐

No

☐

If yes what is that diagnosis?

.....

Has your child ever been described as having the following? (please tick)

Learning  
Disability

☐

Developmental  
Delay

☐

Learning  
Difficulty

☐

Other  
(please specify)

.....  
.....  
.....

What do you understand this to mean?

.....  
.....  
.....  
.....  
.....

At what age was your child diagnosed? (If your child has more than one diagnosis please state at what age they received each diagnosis)

Age.....

Who gave the diagnosis?

GP

☐

Paediatrician

☐

Other (please specify)

.....  
.....  
.....

Have you been given information by professionals: (please tick)

At different times as your child has developed ☐

Just once at the time of diagnosis ☐

Have not received any information ☐

Please circle how much information you have been given about your child's difficulties and how satisfied you have been with the information from different sources.

**Source of Information**

**Amount of information**

**Satisfaction**

**GP**

0 1 2 3 4 5

0 1 2 3 4 5

None

A lot

Dissatisfied

Very Satisfied

**Community Nurse/ Health Visitor**

0 1 2 3 4 5

0 1 2 3 4 5

None

A lot

Dissatisfied

Very Satisfied

**Paediatrician**

0 1 2 3 4 5

0 1 2 3 4 5

None

A lot

Dissatisfied

Very Satisfied

**Education/School**  
e.g. Teacher,  
Educational  
Psychologist

0 1 2 3 4 5

0 1 2 3 4 5

None

A lot

Dissatisfied

Very Satisfied

Source of Information	Amount of information						Satisfaction					
Speech & Language Therapist	0	1	2	3	4	5	0	1	2	3	4	5
	None			A lot			Dissatisfied			Very Satisfied		

Support Organisation e.g. Scottish Society for Autism	0	1	2	3	4	5	0	1	2	3	4	5
	None			A lot			Dissatisfied			Very Satisfied		

Internet/Books	0	1	2	3	4	5	0	1	2	3	4	5
	None			A lot			Dissatisfied			Very Satisfied		

Other (please specify) ..... .....	0	1	2	3	4	5	0	1	2	3	4	5
	None			A lot			Dissatisfied			Very Satisfied		

Other (please specify) ..... .....	0	1	2	3	4	5	0	1	2	3	4	5
	None			A lot			Dissatisfied			Very Satisfied		

Are there any further comments you would like to make about the information you have received about your child’s difficulties?

.....

.....

.....

.....

.....

Thank you very much for your time

## Appendix IV: Inter-rater reliability of the Demographic, diagnosis and information questionnaire

The tick box questions were analysed using Kappa as a measure of agreement

Questionnaire item	Statistic	Significance
Does your child have a specific diagnosis	Kappa = .800	p = 0.010
Has your child been described as having a Learning Disability?	Kappa = 1.000	p = 0.002
Has your child been described as having a Developmental Delay?	Kappa = 1.000	p = 0.002
Has your child been described as having a Learning Difficulty?	Kappa = 1.000	p = 0.002
Who gave the diagnosis: GP?	Kappa = 1.000	p = 0.002
Paediatrician?	Kappa = 1.000	p = 0.002
Other?	Kappa = 1.000	p = 0.002
When was information given: at different times?	Kappa = 1.000	p = 0.002
Once at time of diagnosis?	Kappa = 1.000	p = 0.002
Not received any information	Kappa = 1.000	p = 0.002



The questions that produced numerical scores were analysed using a Pearson's correlation.

Questionnaire item	Pearson's correlation	Significance
Amount of information from GP	$r = 1.000$	Complete agreement between raters
Satisfaction with information from GP	$r = 1.000$	Complete agreement between raters
Amount of information from community nurse/health visitor	$r = 1.000$	Complete agreement between raters
Satisfaction with information from community nurse/health visitor	$r = 1.000$	Complete agreement between raters
Amount of information from education/school	$r = 1.000$	Complete agreement between raters
Satisfaction with information from education/school	$r = 1.000$	Complete agreement between raters
Amount of information from Speech and Language	$r = 1.000$	Complete agreement between raters
Satisfaction with information from speech and language	$r = 1.000$	Complete agreement between raters
Amount of information from support organisation	$r = 1.000$	Complete agreement between raters
Satisfaction with information from support organisation	$r = 1.000$	Complete agreement between raters
Amount of information from internet/books	$r = 1.000$	Complete agreement between raters
Satisfaction with information from internet/ books	$r = 1.000$	Complete agreement between raters
Amount of information from other source	$r = 1.000$	Complete agreement between raters
Satisfaction with information from other source	$r = 1.000$	Complete agreement between raters
Amount of information from other source	$r = 1.000$	Complete agreement between raters
Satisfaction with information from other source.	$r = 1.000$	Complete agreement between raters
Number of sources of information	$r = 1.000$	Complete agreement between raters
Amount of information	$r = 1.000$	Complete agreement between raters
Mean satisfaction with information received	$r = 1.000$	Complete agreement between raters

# FAMILY SUPPORT SCALE (FSS)

## (ADAPTED FROM DUNST, JENKINS AND TRIVETTE)

Listed below are sources of support that are often helpful to members of families raising a young child. This questionnaire asks you to indicate how helpful each source is to *your family*.

Please *circle* the response that best describes how helpful the sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (not available) response.

1. My parents
2. My partner/spouse's parents
3. My relatives/kin
4. My partner/spouse's relatives/kin
5. Partner/spouse
6. My friends
7. My partner/spouse's friends
8. My own children
9. Other parents
10. Co-workers
11. Parent groups
12. Social groups/clubs
13. Place of worship/religious organization
14. My family or child's doctor
15. Professional helpers (social workers, therapists, teachers, etc.)
16. Professional agencies (public health, social services, mental health, etc)
17. School/day-care centre
18. Early intervention programme
19. \_\_\_\_\_
20. \_\_\_\_\_

	Not available	Not helpful at all	Sometimes helpful	Generally helpful	Very helpful	Extremely helpful
1. My parents	NA	1	2	3	4	5
2. My partner/spouse's parents	NA	1	2	3	4	5
3. My relatives/kin	NA	1	2	3	4	5
4. My partner/spouse's relatives/kin	NA	1	2	3	4	5
5. Partner/spouse	NA	1	2	3	4	5
6. My friends	NA	1	2	3	4	5
7. My partner/spouse's friends	NA	1	2	3	4	5
8. My own children	NA	1	2	3	4	5
9. Other parents	NA	1	2	3	4	5
10. Co-workers	NA	1	2	3	4	5
11. Parent groups	NA	1	2	3	4	5
12. Social groups/clubs	NA	1	2	3	4	5
13. Place of worship/religious organization	NA	1	2	3	4	5
14. My family or child's doctor	NA	1	2	3	4	5
15. Professional helpers (social workers, therapists, teachers, etc.)	NA	1	2	3	4	5
16. Professional agencies (public health, social services, mental health, etc)	NA	1	2	3	4	5
17. School/day-care centre	NA	1	2	3	4	5
18. Early intervention programme	NA	1	2	3	4	5
19. _____	NA	1	2	3	4	5
20. _____	NA	1	2	3	4	5



© 1993, Dunst, Trivette and Hamby. *Family Support Scale* by Carl J. Dunst, Carol M. Trivette and Deborah W. Hamby from Dunst, C. J., Trivette, C. M. and Deal, A. G. (Eds) (1994). *Supporting and Strengthening Families, Volume 1: Methods, Strategies and Practices*. Reproduced by kind permission of the authors and publishers, Brookline Books, Cambridge, MA.

This measure is part of *The Child Psychology Portfolio* edited by Irene Sclare. Once the invoice has been paid, it may be photocopied for use **within the purchasing institution only**. Published by The NFER-NELSON Publishing Company Ltd, Darville House, 2 Oxford Road East, Windsor, Berkshire SL4 1DF, UK. Code 4059054

# A SHORT-FORM OF THE QUESTIONNAIRE ON RESOURCES AND STRESS (QRS-F)

This questionnaire asks about your feelings about a child in your family. There are many blanks in the questionnaire. Imagine the child's name filled in on each blank. Give your honest feelings and opinions. Please answer all the questions, even if they do not seem to apply. If it is difficult to decide whether to circle True (T) or False (F), answer in terms of what you or your family feel or do *most* of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False, even then. Please remember to answer all of the questions.

- |   |   |
|---|---|
| 1. _____ doesn't communicate with others of his/her age group   | <input type="checkbox"/> T <input type="checkbox"/> F |
| 2. Other family members do without things because of _____  | <input type="checkbox"/> T <input type="checkbox"/> F |
| 3. Our family agrees on important matters   | <input type="checkbox"/> T <input type="checkbox"/> F |
| 4. I worry what will happen to _____ when I can no longer take care of him/her  | <input type="checkbox"/> T <input type="checkbox"/> F |
| 5. Constant demands to care for _____ limit the growth and development of someone else in our family                    | <input type="checkbox"/> T <input type="checkbox"/> F |
| 6. _____ is limited in the kind of work he/she can do to make a living  | <input type="checkbox"/> T <input type="checkbox"/> F |
| 7. I have accepted that _____ might have to live out his/her life in a special setting (e.g. institution or group home) | <input type="checkbox"/> T <input type="checkbox"/> F |
| 8. _____ can feed himself/herself   | <input type="checkbox"/> T <input type="checkbox"/> F |
| 9. I have given up things I really wanted to care for _____   | <input type="checkbox"/> T <input type="checkbox"/> F |
| 10. _____ is able to fit into the family social group   | <input type="checkbox"/> T <input type="checkbox"/> F |
| 11. Sometimes I avoid taking _____ out in public  | <input type="checkbox"/> T <input type="checkbox"/> F |
| 12. In the future, our family's social life will suffer because of increased responsibilities and financial stress      | <input type="checkbox"/> T <input type="checkbox"/> F |
| 13. It bothers me that _____ will always be this way  | <input type="checkbox"/> T <input type="checkbox"/> F |
| 14. I feel tense whenever I take _____ out in public  | <input type="checkbox"/> T <input type="checkbox"/> F |
| 15. I can go to visit friends whenever I want   | <input type="checkbox"/> T <input type="checkbox"/> F |
| 16. Taking _____ on holiday spoils pleasure for the whole family  | <input type="checkbox"/> T <input type="checkbox"/> F |
| 17. _____ knows his/her own address   | <input type="checkbox"/> T <input type="checkbox"/> F |
| 18. The family does as many things together now as we ever did  | <input type="checkbox"/> T <input type="checkbox"/> F |



19. \_\_\_\_\_ is aware of who he/she is   T     F
20. I get upset with the way my life is going   T     F
21. Sometimes I feel very embarrassed because of \_\_\_\_\_   T     F
22. \_\_\_\_\_ doesn't do as much as he/she should be able to do.   T     F
23. It is difficult to communicate with \_\_\_\_\_ because he/she has difficulty understanding what is being said to him/her   T     F
24. There are many places we can enjoy ourselves as a family when \_\_\_\_\_ comes along   T     F
25. \_\_\_\_\_ is over-protected   T     F
26. \_\_\_\_\_ is able to take part in games or sports   T     F
27. \_\_\_\_\_ has too much time on his/her hands   T     F
28. I am disappointed that \_\_\_\_\_ does not lead a normal life   T     F
29. Time drags for \_\_\_\_\_, especially free time   T     F
30. \_\_\_\_\_ can't pay attention for very long   T     F
31. It is easy for me to relax   T     F
32. I worry what will happen to \_\_\_\_\_ when he/she gets older   T     F
33. I get almost too tired to enjoy myself   T     F
34. One of the things I appreciate about \_\_\_\_\_ is his/her confidence   T     F
35. There is a lot of anger and resentment in our family   T     F
36. \_\_\_\_\_ is able to go to the bathroom alone   T     F
37. \_\_\_\_\_ can't remember what he/she says from one moment to the next   T     F
38. \_\_\_\_\_ can ride on a bus   T     F
39. It is easy to communicate with \_\_\_\_\_   T     F
40. Constant demands to care for \_\_\_\_\_ limit my growth and development   T     F



41. \_\_\_\_\_ accepts himself/herself as a person ☐ T ☐ F
42. I feel sad when I think of \_\_\_\_\_ ☐ T ☐ F
43. I often worry what will happen to \_\_\_\_\_ when I can no longer take care of him/her ☐ T ☐ F
44. People can't understand what \_\_\_\_\_ tries to say ☐ T ☐ F
45. Caring for \_\_\_\_\_ puts a strain on me ☐ T ☐ F
46. Members of our family get to do the same kinds of things that other families do ☐ T ☐ F
47. \_\_\_\_\_ will always be a problem to us ☐ T ☐ F
48. \_\_\_\_\_ is able to express his/her feelings to others ☐ T ☐ F
49. \_\_\_\_\_ has to use a bedpan or a nappy ☐ T ☐ F
50. I rarely feel blue ☐ T ☐ F
51. I am worried much of the time ☐ T ☐ F
52. \_\_\_\_\_ can walk without help ☐ T ☐ F



© Friedrich, 1983. *Questionnaire on Resources and Stress* by William Friedrich from Friedrich, W. N., Greenberg, M. T. and Cmic, K., 'A short-form of the Questionnaire on Resources and Stress', *American Journal of Mental Deficiency*, Vol. 88, 41-48, 1983. Reproduced by kind permission of the author and the publishers, the American Association on Mental Retardation, Washington, DC.

This measure is part of *The Child Psychology Portfolio* edited by Irene Scare. Once the invoice has been paid it may be photocopied for use **within the purchasing institution only**. Published by The NFER-Nelson Publishing Company Ltd, Darville House, 2 Oxford Road East, Windsor, Berkshire SL4 1DF, UK. Code 405905

## **Appendix VII: Information sheet and consent form**

Each parent invited to take part in the research was sent the following information sheet and consent form. The information sheet varied slightly for each area as it specified who had given permission for the research to be carried out in the area participants were from. The example enclosed is for Edinburgh special schools.



## **Information Sheet**

We would like you to take part in a research study. Please take time to read the information carefully before you decide whether to take part in the study.

### **What is the study about?**

The study is about the amount of stress parents experience and how much information and support they can access in relation to their child. The study is interested in looking at these factors in families who have a child with a learning disability.

Research has found that the stress families with a child with disabilities experience can vary according to many different factors. In particular we are interested in whether the amount of stress parents experience and the amount of information and support they can access is different for parents depending on whether their child has a specific diagnosis e.g. autistic spectrum disorder or a more general diagnosis such as learning disability.

You have been chosen because your child attends a special school and it is therefore likely that they may have a learning disability and/or more specific diagnosis.

If you agree to take part in the study we would ask you to sign a copy of the enclosed consent form and return it to me along with the questionnaires. If you change your mind about taking part in the study at any time you have a right to withdraw from the study and do not have to give a reason why.

Taking part in the study will have no impact on your child's education or the treatment they receive from any services who may be involved with your child.

### **What will it involve?**

You will be asked to complete three questionnaires asking:

- whether your child has a specific diagnosis, where you have received information about your child's difficulties from and how happy you have been with this information,
- about the support you access in relation to your child and how happy you are with this support
- about stress you may experience and the nature of your child's difficulties.

**What will happen with the results of the study?**

All the consent forms and questionnaires will be treated as confidential and will be kept in a locked filing cabinet.

The results will be put together in a report and this will be submitted to the University of Edinburgh as part of a doctorate in clinical psychology. The University of Edinburgh will keep a bound copy of the report and it maybe written up later for publication. No names or other identifying information will be contained in the report.

It is hoped that the study will improve the knowledge clinical psychologists have about the stress families with a child with a learning disability experience and the amount of information and support they can access for their child. In the longer term it is hoped this will lead to improving the information and support families receive in relation to their child's difficulties.

The Director of Children and Families has agreed for this research to be carried out.

You will have a copy of this information sheet and the consent form to keep.

**Contact information**

If you require anymore information about the research study or you would like the researcher to visit you at home to help you complete the questionnaires please contact the researcher:

Address: Rhiannon Howie-Davies  
Trainee Clinical Psychologist  
CAMHS  
1 Randolph Road  
STIRLING  
FK8 2AU

Email: rhiannonhowiedavies@hotmail.com      telephone: 01786 450591

**What happens next?**

Please think about the information carefully and decide whether you would like to take part in the study. If you would like to take part in the study please complete the consent form and questionnaires and return them in the enclosed envelope.



Information, Support and Parental Stress in Families with a Child  
with a Learning Disability

Researcher: Rhiannon Howie-Davies  
1 Randolph Road  
STIRLING  
FK8 2AU

CONSENT FORM

I (full name).....  
consent to participate in the research study. I have read and  
understood the information leaflet. I understand that that I can  
withdraw from the study at any time and do not have to give a  
reason why.

Signed.....  
Date.....

Please return all forms in the envelope provided  
THANK YOU

**Appendix VIII: Correspondence with Stirling Council regarding ethical approval**

COPY



SCHOOL OF HEALTH IN SOCIAL SCIENCE

Please reply to  
Rhiannon Howie-Davies  
The Manor  
Brown Street  
Camelon  
FALKIRK  
FK1 4PQ

The University of Edinburgh  
The Medical School  
Teviot Place  
Edinburgh EH8 9AG  
Telephone 0131 650 1000  
or direct dial 0131 650  
Fax 0131 650 3891

7th Dec

David Cameron  
Director of Children's Services  
Stirling Council  
Viewforth  
STIRLING  
FK8 2ET

Dear Mr Cameron

I am a third year Trainee Clinical Psychologist on the University of Edinburgh/NHS Scotland D.Clin.Psychol course and I am currently on a year long placement in Forth Valley. I am conducting a research project as part of my doctoral qualification.

The research involves the participation of parents of pupils attending special schools. I aim to investigate the impact of different diagnoses on the information and support families can access with regard to their child's difficulties and the impact of this on parental stress.

I have included an outline of the research methodology and the information and consent forms I plan to use with parents. I would be grateful if you could read the enclosed documents and provide ethical approval for my study to access participants through special schools in the Stirling area. I am happy to provide you with any further information you require or discuss the research with you by phone or in person.

Yours sincerely

Rhiannon Howie-Davies  
Trainee Clinical Psychologist

Dr Karen McKenzie  
Consultant Clinical Psychologist  
& Academic Supervisor

23 DEC 2005



Rhiannon Howie-Davies  
CAMHS  
The Manor  
Brown Street  
Camelon  
Falkirk  
FK1 4PQ

**Children's Services**

Stirling Council

Viewforth

Stirling

FK8 2ET

DX. ST 28

Tel. 01786 442526

Fax. 01786 442782

Head of Service: Jim McAlpine

E-mail: [doranm@stirling.gov.uk](mailto:doranm@stirling.gov.uk)

Our Ref: JMcA/DS

Your Ref:

Dear Rhiannon

**Research Request**

Thank you for completing the pro-forma regarding research which you intend to carry out within three schools in Stirling Council.

I have no difficulty in agreeing to your request subject to headteacher and parental agreement.

I would be grateful if you could inform me, as soon as you know, which three schools you wish to approach.

I enclose signed pro-forma.

Yours sincerely

**Jim McAlpine**  
**Acting Head of Schools**



STIRLING COUNCIL

21 DEC 2005

CHILDREN'S SERVICES

Viewforth  
Stirling  
FK8 2ET  
(01786 442526)

**REQUEST FOR ACCESS TO SCHOOLS FOR  
THE PURPOSE OF EDUCATIONAL RESEARCH**

Your Name: RHIANNON HOWIE-DAVIES (MRS)
Your Address: CAMHS, THE MANOR, BROWN STREET, CAMELON, FALKIRK, FK1 4PQ
Your Post: TRAINEE CLINICAL PSYCHOLOGIST
Your Employer: ON NHS SCOTLAND/UNIVERSITY OF EDINBURGH COURSE, EMPLOYED BY NHS Lothian BUT ATTACHED TO NHS FORTH VALLEY FOR ALL CLINICAL PLACEMENTS
Title of your Project: INFORMATION, SUPPORT AND PARENTAL STRESS IN FAMILIES WITH A CHILD WITH A LEARNING DISABILITY
Context and purpose of the research (e.g. M.Ed dissertation, personal study, project funded by SOEID) D.CLIN. PSYCHOL THESIS
<p>Give a brief outline of the research, indicating the kind of information you will be gathering and the main questions the research is trying to answer</p> <p>The research study is interested in the impact a child's diagnosis has on the information and support families receive and parental stress. In particular are there differences between families with a child with a broad learning disability diagnosis and those with a child with a more specific diagnosis eg Autistic Spectrum Disorder? This will be measured through the use of questionnaires (please see enclosed).</p> <p>Please see attached for specific research questions.</p>

When do you intend to begin your work with schools/teachers? JANUARY 2006
When do you expect to complete your work with schools/teachers? SCHOOLS WILL ONLY BE INVOLVED WITH THE RECRUITMENT OF PARTICIPANTS WHICH SHOULD BE COMPLETED BY MARCH 2006
When will the research as a whole be completed? 1ST AUGUST 2006
What would you be asking schools or teachers to do? (e.g. fill in 6 page questionnaire, 40 minute interview, allow observation of six lessons) TO PROVIDE CONTACT ADDRESSES OF PARENTS FOR INFORMATION SHEETS AND QUESTIONNAIRES TO BE SENT TO .

(If you have a draft questionnaire or schedule for interview or observation, please attach a copy to this form).

How many schools and teachers would be involved? THREE SCHOOLS, HEADTEACHERS AND POTENTIALLY ADMIN STAFF
How much time would be involved for each individual during working hours? MINIMAL TIME FROM SCHOOL STAFF TO PROVIDE CONTACT INFORMATION
How much time would be involved for each individual outside working hours? PARENTS OF CHILDREN ATTENDING THE SPECIAL SCHOOLS WOULD BE ASKED TO COMPLETE THREE QUESTIONNAIRES APPROXIMATELY 45 MINUTES
Please state any way in which the research would involve pupils: ONLY PARENTS WILL BE INVOLVED
Is any organisation involved in any way? NO

To whom will you be reporting your research, and in what form?

THE UNIVERSITY OF EDINBURGH, SUBMITTED AS A THESIS

Are you willing to provide Stirling Council Children's Services with a summary of your findings:

YES

Please list any specific schools you plan to involve:

KILDEAN SCHOOL

WHINS OF MILTON SCHOOL

OCHIL HOUSE, WALLACE HIGH SCHOOL

Any other information you wish to add:

Please find enclosed, research methodology, information sheet, consent form and the three questionnaires parents will be asked to complete.

**FOR AUTHORITY USE ONLY**

This request for research access has the support of Stirling Council Children's Services

Signed;

Date: 22-12-05

11

**Appendix IX: Correspondence with Clackmannanshire Council  
regarding ethical approval**





SCHOOL OF HEALTH IN SOCIAL SCIENCE

Please reply to  
Rhiannon Howie-Davies  
The Manor  
Brown Street  
Camelon  
FALKIRK  
FK1 4PQ

The University of Edinburgh  
The Medical School  
Teviot Place  
Edinburgh EH8 9AG  
Telephone 0131 650 1000  
or direct dial 0131 650  
Fax 0131 650 3891

7<sup>th</sup> December 2005

Dave Jones  
Director of Services to People  
Lime Tree House  
Castle Street  
ALLOA  
FK10 1EX

Dear Mr Jones

I am a third year Trainee Clinical Psychologist on the University of Edinburgh/NHS Scotland D.Clin.Psychol course and I am currently on a year long placement in Forth Valley. I am conducting a research project as part of my doctoral qualification.

The research involves the participation of parents of pupils attending special schools. I aim to investigate the impact of different diagnoses on the information and support families can access with regard to their child's difficulties and the impact of this on parental stress.

I have included an outline of the research methodology and the information and consent forms I plan to use with parents. I would be grateful if you could read the enclosed documents and provide ethical approval for my study to access participants through special schools in the Clackmannanshire area. I am happy to provide you with any further information you require or discuss the research with you by phone or in person.

Yours sincerely

Rhiannon Howie-Davies  
Trainee Clinical Psychologist

Dr Karen McKenzie  
Consultant Clinical Psychologist  
& Academic Supervisor



# The Psychological Service

15 Mar Street, Alloa  
Telephone: 01259 226000 Fax: 01259 226006



CLACKMANNANSHIRE

COUNCIL

Services to People

Contact: Mike O'Connor  
Principal Psychologist

Direct Tel: 01259 226000

Our Ref: MOC/KA

Your Ref:

Date: 5 January 2006

Rhiannon Howie-Davies  
The Manor  
Brown Street  
Camelon  
FALKIRK  
FK1 4PQ

Dear Rhiannon,

## Research Project

Mr Jones, Director, Services to People, has asked me to respond to your request.

He passed on your letter and outline research project to me.

I would welcome the opportunity of discussing this with you before making any decision. Perhaps, you would telephone me at the above number.

I look forward to hearing from you.

Yours sincerely

Mike O'Connor  
Principal Psychologist



# The Psychological Service

15 Mar Street, Alloa  
Telephone: 01259 226000 Fax: 01259 226006



CLACKMANNANSHIRE

COUNCIL

Services to People

Rhiannon Howie-Davies  
The Manor  
Brown Street  
Camelon  
Falkirk  
FK1 4PQ

Contact: Mike O'Connor  
Principal Psychologist

Direct Tel: 01259 226000

Our Ref: MOC/KA  
Your Ref:

Date: 8 March 2006

Dear Rhiannon,

I am writing to provide you with a formal response to the request contained in your letter to Dave Jones, Director of Services to People, dated 7 December 2005.

When we met here in my office on 20 January we discussed the details of your research project. I can confirm on behalf of Clackmannanshire Council that approval has been given to you to conduct the research project as outlined in your letter 7 December and as discussed at our meeting on 20 January.

Yours sincerely

Mike O'Connor  
Principal Psychologist

**Appendix X: Correspondence with Edinburgh City Council  
regarding ethical approval**



SCHOOL OF HEALTH IN SOCIAL SCIENCE

Please reply to  
Rhiannon Howie-Davies  
The Manor  
Brown Street  
Camelon  
FALKIRK  
FK1 4PQ

The University of Edinburgh  
The Medical School  
Teviot Place  
Edinburgh EH8 9AG  
Telephone 0131 650 1000  
or direct dial 0131 650  
Fax 0131 650 3891

20<sup>th</sup> January 2006

Mr Roy Jobson  
Director of Children and Families  
Children and Families Department  
The City of Edinburgh Council  
Wellington Court  
10 Waterloo Place  
Edinburgh  
EH1 3EG

Dear Mr Jobson

I am a third year Trainee Clinical Psychologist on the University of Edinburgh/NHS Scotland D.Clin.Psychol course and I am conducting a research project as part of my doctoral qualification.

The research involves the participation of parents of pupils attending special schools. I aim to investigate the impact of different diagnoses on the information and support families can access with regard to their child's difficulties and the impact of this on parental stress.

I have included an outline of the research methodology and the information and consent forms I plan to use with parents. I would be grateful if you could read the enclosed documents and provide ethical approval for my study to access participants through special schools in the Edinburgh area. I am happy to provide you with any further information you require or discuss the research with you by phone or in person.

Yours sincerely

Rhiannon Howie-Davies  
Trainee Clinical Psychologist

Dr Karen McKenzie  
Consultant Clinical Psychologist  
& Academic Supervisor

# • EDINBURGH •

THE CITY OF EDINBURGH COUNCIL

- 6 FEB 2006

## CHILDREN AND FAMILIES

Ms Rhiannon Howie-Davies  
The Manor  
Brown Street  
Camelon  
FALKIRK  
FK1 4PQ

3 February 2006

Dear Ms Howie-Davies,

### **Research on Learning Disability and Parental Stress**

I am writing to you in response to your letter of 20 January 2006, concerning the above. Your request for approval to carry out this research in City of Edinburgh schools has been considered by senior staff of the Authority with responsibility for Additional Support Needs.

While the staff concerned find the research proposal interesting and potentially valuable, the sensitive nature of the approaches you propose to make to parents has made it necessary, in their view, to have advance sight of the questionnaires you propose to use. (You enclosed only the Information Sheet for parents and the Consent Form with your letter.) Additionally, the view of the staff concerned is that it would not be appropriate to approach all fourteen of the City of Edinburgh's Special Schools, due to the wide range of children attending different establishments.

I should therefore be grateful if you could send me copies of the questionnaires you propose to use, so that we can give these further consideration. I would suggest also that you might wish to speak to our Quality Improvement Officer (Support for Learning) to discuss which schools it would be most appropriate to approach. She is Mrs Rosie Wilson, and can be contacted on 0131-469 3022.

Yours sincerely,

Graham H Munn  
Quality Development  
Manager, Support Services

3 MAR 2006

# • EDINBURGH •

THE CITY OF EDINBURGH COUNCIL

## CHILDREN AND FAMILIES

Ms Rhiannon Howie-Davies  
Trainee Clinical Psychologist  
CAMHS  
The Manor  
Brown Street  
Camelon  
FALKIRK  
FK1 4PX

1 March 2006

Dear Ms Howie-Davies,

### **Research on Learning Disability and Parental Stress**

I am writing to you in response to your letter of 15 February 2006 with which you enclosed the questionnaires you intend to use in connection with the above research.

I am pleased to confirm that, in the light of this additional information about the project, you have approval in principle from the Children and Families Department to carry out the research you propose, as outlined in your letter and earlier correspondence. You will wish to note, however, that it is the policy of this Authority to leave final discretion on participation in research projects to Head Teachers and their staff, so that approval in principle does not oblige any particular establishment to take part.

I note that you intend to contact Mrs Rosie Wilson, our Quality Improvement Officer in this area of work, and I confirm that she has indicated that she will be happy to discuss the research with you. Her telephone number, as previously notified, is 0131-469 3022. Her e-mail address is [rosie.wilson@educ.edin.gov.uk](mailto:rosie.wilson@educ.edin.gov.uk)

I would like to wish you success with the research,

Yours sincerely,

Graham H Munn  
Quality Development  
Manager, Support Services